

## PART 2:

### The Interviews

Edited for clarity and listed in alphabetical order based on the fictitious names.

*Aasami, mom Satya, age 11*

“Her stutter started around age five. The school speech therapist said they couldn’t help because it was not affecting her academics. When she was seven, we sought out a private speech therapist. Like many parents who don’t stutter themselves but have a child who stutters, I just assumed it was about contacting a speech therapist like we did for our daughter’s older brother when he couldn’t say his r’s. He needed speech therapy, so we went to the same place with our daughter.

The speech therapist was lovely and at first Satya was excited to go play games, but nothing changed her stutter and I felt that there was no progress being made. I was still in the mindset that she needed to be fixed because no one was speaking to me about how I need to change my attitude.

We were noticing as she was getting older, she was talking less and her self-esteem was going down. Everyone started to notice. Even though her current speech therapist was lovely, she did not address what was going on underneath—what we now know as the stuttering iceberg\* We were starting to realize that telling her things like “just slow down” was never going to help.

**A turning point:**

We eventually got help from school and Satya got a speech individualized educational plan and the new school-based speech therapist. This speech therapist had interned with the American Institute for Stuttering (AIS) in New York City, an organization that focused on acceptance, avoidance, parent involvement, and self-esteem. She told us, “You need to forget everything you think about stuttering.” She was very gentle about it. We were really lucky to have stumbled on to this organization’s way of therapy.

**“Things turned around and after one year, she’s like a different person.”**

Our daughter saw the new school-based speech therapist once a week and we also started seeing a therapist at AIS. We were lucky. We had experienced two years of traditional speech therapy and things could have gotten bad. Her self-esteem was starting to plummet. Things turned around and after one year, she’s like a different

person.

One of the biggest changes is that this therapist is a person who stutters so Satya has this weekly meeting with someone who understands her completely. I also get time with him and it’s so helpful. Here’s an adult who knows what it’s like to stutter and who has this great ethos. The combination of him and the school-based speech therapist completely changed the way I think. That was of huge importance because I’m with her all the time. My attitude being different has hugely helped her. I’m not making faces or going ‘please start again, slow down, etc.’ I’m not doing any of that.

It’s a journey. We attended parent group meetings with AIS and there was a lovely couple who had a six-year-old daughter and hadn’t started with a speech therapist. The father was still very much in that place of fixing. It was great because he had all these people and specialists who could explain that it needs to be a different approach. Then I realized, ‘That was me not so long ago!’

Our daughter is now into speed skating and loves roller derby. She's very artistic, loves baking and plays the flute. She's just about to start middle school so we're taking a big deep breath. She wants to get some pink in her hair. She's wanting to make a bit of a splash.

Having stumbled into this therapy, well, I'm constantly thinking, 'We've been so lucky, we dodged a bullet.' I can't believe where I am now compared to where I was, and it didn't take long. Her mental health, that is the most important thing as far as I'm concerned.

Fix or protect. I wanted to fix her because I wanted to protect her. There's nothing wrong with my kid. It's a gift, she can go out and tell people, 'this isn't a problem as long as I'm speaking.'",

\*<https://www.stutteringhelp.org/blog/sheehan-stuttering-analogy>

*Abigail, mom to Oliver, age 10*

“The National Health Service (NHS) assured me that Oliver’s speech was completely normal, and this was quite often what happened when children started to speak. It got to where he would open his mouth and nothing would come out. It was really distressing. His stammer got a bit better, but I knew something was not right. He was the first person in our family to stammer. I was really frightened. I know adults who are completely debilitated by it.

We started seeing an NHS speech therapist. She did Lidcombe. I didn’t know anything about stammering at all. This was completely uncharted territory. You had to correct him and tell him that what he was doing was wrong. I had to record the severity levels of the fluency throughout the day, every day.

We were looking at it 4-6 weeks later and the NHS speech therapist said, ‘this is not working, and we’ve evidenced that with paperwork you’ve kept.’ I thought she was discharging him but if anything, he was getting worse. Then she said she was going to connect with the Michael Palin Centre for Stammering (MPC) in London, an organization that specialized in parent-child interaction therapy for families with children who stammer.

### **The turning point:**

We started trying to implement parent child interaction therapy while Oliver was on their waiting list. Our speech therapist had put forward a lot of information about our son to the NHS and he managed to get fast tracked.

We were filmed interacting with him while in therapy. I had done two sessions of parent child interaction therapy workshops without our son and came back with loads of information. Our original speech therapist and I worked through it all and then we met with a speech therapist from MPC. We were given lots of strategies and tips. As soon as we started, his stammer began to improve. One day the original speech therapist turned up and asked, ‘have you heard of this book? I’d really like it if you’d read it.’ It was *Voice Unearthed*. I couldn’t put it down and I was crying as I was reading it. I couldn’t believe it—there were so many similarities.

**“Parent child interaction therapy was about us connecting with our child and feeding off the fluency he has.”**

There was one line in your book—you turned ‘like an owl’s head’ when your child started talking. That’s just what you do as a parent. I think I made myself quite ill with worry. I would meet with friends who had children the same age and they were worrying about different milestones and all I could think of was ‘I just want him to speak!’ You’re just powerless without a voice. The pain I felt was counterproductive. It’s hard to manage your body language. When my husband got involved through MPC parent-child interaction therapy, he said, ‘can you think about your facial expressions? When our son is saying the same word over and over again, your face looks like it’s in physical pain and we need to get him to relax and not worry about it.’ This is hard to do when inside you’re consumed with worry.

Without a shadow of a doubt his fluency improved once we stopped doing Lidcombe. The impact you’ve had on our life as a whole family and on our son is just amazing. If there’s anything I can do—if it could help one other person with the turmoil and emotional energy you

go through when your child struggles with the basic ability to talk. Voice Unearthed was a really changing point. I would easily take a day off work and school to go into this medical center in London. Why couldn't we take a day off work, pull our son out of school so he's just the only child with no pressure, no siblings, and do something fun—like go to the zoo or natural history museum?

Our original speech therapist was very open-minded. She could see the weakness in what she was doing and that it was damaging him as opposed to benefiting him. We transitioned to investing our time and energy in just being happy with him—not having tallies and tik charts and documenting our special time. That was the end of it. Sometimes his words are bumpy but that's just the way he talks.”

*Alma, age 35*

“The really hard thing for parents to understand is that there is a chance that this problem is never going away as such. And by the problem, I mean just the sensation of sometimes you want to say something and there’s a wall there—you cannot just fluently say that word. And then the question is ‘how does somebody deal with that?’ That’s a decision the person has to make for themselves, no one can make for them.

I did end up in fluency-shaping therapy, but I suspect that the early speech therapy at my school was a sort of avoidance reduction approach. I think the therapist thought ‘I know I can’t treat this properly, I know I don’t have the expertise, so I will just help these kids be confident in themselves.’

After that I realized that most speech therapy was about using therapy techniques to make other people more comfortable with how I talk. I pursued therapy techniques and realized that it was at the cost to myself—an emotional cost and a cost in opportunity if I choose not to say or do certain things because I might stutter. There was also a cost just in terms of mental energy that goes into fluency shaping therapy and the sheer amount of things I had to keep track of when I was talking. That’s energy I’m not spending on other things. I am the only person who has to live with this 24-hours a day, seven days a week. Why am I prioritizing other people over myself?

I choose for me. The least cost is that I just stutter so that’s what I go with. Other people who stutter make that decision differently. It’s really something for them to decide. If you, as a parent, push your kid into speech therapy, especially into fluency shaping, you’re trying to make that decision for them. I would probably try and restructure this to be more sympathetic. Of course, for the parent it’s this really terrible thing to think ‘this kid, this child I love, may have to struggle with this for the rest of their life.’ It’s not always an easy journey and there’s a cost associated with every option.

If a kid grows out of stuttering, then they don’t need speech therapy. They’re the ones who can put that experience behind them and go on to live a normal fluent life. For the kids who do continue to stutter, if you attack that the wrong way you can give them life-long emotional problems. There is evidence -I’m just going to point at your entire first book here.

The stuttering on its own is not nearly as bad as people think. Early on I developed a mindset to be confident and anybody who made an issue of my speech was an asshole who was not worth my time. Now I’m able to live my life and yes, sometimes I just need a little longer to say something. People overall have been really great about it.

I wanted to be a lecturer for a long time and I did a PhD in pure mathematics. This was one of my more questionable life choices in retrospect. I didn’t continue with that, having nothing to do with the public speaking. I enjoyed doing the lectures and I enjoyed doing the tutorials. I will still take the opportunity to do public speaking when I can. At some point I just decided that I am not afraid of stuttering. Sometimes I stutter more but that’s okay. Some people mumble and some people have really strong foreign accents.

I fell into a mindset of avoidance for a bit and then realized I did not want to be there, so I dragged myself back out. What really hurts is when you fall into the mindset that if you stutter you’re failing at something and it’s your job to make your speech more comfortable for those around you. That’s where the pain comes in.

I am a software developer now and it's really great because I have that team around me, and I always have somebody to talk to. I sometimes wonder if it's more likely for people who stutter to end up being more outgoing and extraverted? I get so angry about the media stereotypes and fiction about people who stutter, like when they say, 'oh they stutter because they're shy.' In reality you cannot be shy when you stutter. The instant you open your mouth, all the attention gets drawn on you. When you stutter, you're used to being really memorable. I spent a few years pretty much fluent and what bothered me was that I didn't know if people would remember me!

**“What really hurts is when you fall into the mindset that if you stutter you're failing at something and it's your job to make your speech more comfortable for those around you. That's where the pain comes in.”**

A lot of speech therapists have almost no training on stuttering. They are used to dealing with speech disorders that are amenable to therapy, like stroke victims and lisps. It's completely counter-intuitive that this approach is deadly for people who stutter.

I remember talking to a speech therapist at a conference in Glasgow. She was saying all the right things and nodding and agreeing with me and I was like 'okay maybe this person knows what it's about.' Then she said something like 'yes, and when we've kind of dealt with all this emotional damage and we've taught them not to avoid' and blah blah blah. Then we can start dealing with the actual problem.' I'm like, 'Wait a second. What actual problem? You and I are not talking about the same thing. You think we are, but we are really not. To me, if you have a happy confident person who stutters, who's no longer avoiding situations, your job is done.'

If I speak naturally, I stutter. In order not to stutter, I have to speak in some unnatural fashion, somehow, for the rest of my life. That unnatural fashion really takes a lot out of you.

Speech therapy actually made me stutter more and my stutter changed in response to speech therapy techniques. This is how secondary symptoms happen. It happens when you do something when you stutter because it makes you stutter less and eventually it stops helping but you can't stop doing it. So, in that sense there is no difference between me squeezing my eyes shut and me trying to use speech therapy techniques.

I still use a bit of technique to avoid some of my super super long blocks. Getting stuck for 20 or 30 seconds every time you try to introduce yourself isn't fun. But that's the sort of trade off that feels a lot smaller to me than what we've been talking about. It's very much this sort of day-to-day stuff.

It can be dangerous to go to speech therapy. After I came out of therapy where I was trying to get rid of the stutter, my thought was 'You know what? I could use a speech therapist right now to help me untangle what the hell has happened to my speech and try to get back to how I was stuttering before!'"

*Archie, age 41*

“I started stuttering when I was three and therapy started when I was about six. My parents were confused and didn’t know what was out there for resources. I remember them telling me that I had a stutter when I was around six.

My early therapy mostly focused on the therapist talking to the parents as I was playing. I remember being confused over what they were being told at the time. Was it the environment, genes, parents talking too fast, were they were to blame? There was no conversation about needing to be fixed. It was a very warm environment and my relationship with the therapist was good. I did enjoy it. I remember being allowed to play with toys. When I was there, it was okay.

Then therapy changed to focus more on fixing. I remember working with trains a lot—joining up words. The approach was to take my time, take a deep breath, think about sentences as train carriages—join all the words up. I remember concentrating on my breathing, what words I wanted to say, and trying to not take a break in my sentence. My fluency was good when I was using techniques, but it was very tiring. There was too much going on in my brain. I was very confused as to why I was fluent in the clinic setting but couldn’t keep doing it.

My parents’ anxiety was so annoying when I was younger. My mom wanted to talk about it all the time and my dad didn’t. Mom was more ‘How many times did you stutter? Did you practice your techniques? etc.’ One day my dad asked me how school was, and I remember talking and I was really blocking, and he was reading the paper and lifted it so he couldn’t see me. That always stayed with me and when I got older, he shared that he stuttered as a kid, and he felt shame and guilt and felt accountable for it. Not telling me was a crap thing to do, but I understand that more now that I’m a parent.

My therapy stopped when I was 10 because the therapist moved out of the area. I went five to six months without therapy and started again at the beginning of the school year. I felt a connection with my new therapist because he was a guy who stuttered and had long, unkept hair. He was the first person I had met who had a stutter.

I still didn’t really want to go and talk about it again—start all over. My parents were very concerned because I had grown up in the same school and the teachers and young people knew me. Now I was ready to go off to high school—new students and teachers. We still did some fluency shaping in therapy because of the need for measures and outputs. That was about half, the other half, we talked. He asked me how I felt, what my fears were—so that was an eye-opener. This person had forged a career and stuttered. This person cared about how I felt, not just how I was talking.

I saw him for two and one-half years and he did something that was cool. He hired out a studio space and he and a couple of therapists set up a camp. He asked my parents to send me. My parents thought it was a great idea for me to meet other people who stutter. I really just wanted to hang with friends. My parents didn’t speak about it for a couple of months and then in July, my dad got me up and I thought I was going to soccer camp. We were half-way there and he asked why I was in my soccer camp outfit because we were going to this other camp—which was right next door, so I saw all my friends getting out of cars to go to soccer camp. I was mad.

But when I first saw a kid who stuttered, it was powerful. We just hung around for four days. We were gaining a lot of confidence. Part of it was to do with fluency but part of it was to meet others. We did exercises like having to buy a theater ticket. Mostly we just had fun and it made me aware that there were others out there. Unfortunately, the camp only happened once.

High school was daunting. During that time, I stopped therapy. I don't know why. I don't know if it was because my fluency improved, or at least I was using the technique in the clinic setting successfully? I just don't think I spoke a lot. I know I avoided—I was very good at avoiding. My stutter wasn't as strong as I got older which made it easier to hide.

It was hard when my therapy stopped. A lot of the therapy was talk therapy—a lot of sharing. 'What do you find hard in school,' things like that. I wasn't being told what to do, it was just good to just talk. He never advised me to use techniques. He provided them as options and let me make the decision.

What I know would have helped was more support for my parents. They were great, but I think it would have helped for our family unit to access other families and for me to know there were other people out there who stuttered. Not practicing fluency—just being with other kids who stutter. I don't know how much training my first therapist had if any. A parent group would have been helpful for me and my parents. Being provided with other options in therapy—not just focusing on fluency. Being able to talk about my feelings and what I wanted as well. When I was six, I just wanted to play. I was hyper-aware and not being given the opportunity to speak about it.

*Ashley, age 35 (also a speech therapist)*

“I didn’t have therapy as a child but I managed to only talk when I was fluent, so no one really knew I needed it. Then in second grade the teacher called on me and I had a silent block. I started to cry, and kids made fun of me. Still, no one really addressed it.

During my childhood, I would have moments where my stutter peaked and then I would have a mini meltdown. All of a sudden I’m stuck, people are making fun of me, and I’m reminded that something is wrong. I’d be upset for a day or two and then I would just go about my day. It was something that was never addressed. That was my experience as a child.

By middle school I was having a hard time blocking and stalling. Mom took me to a speech therapist who told me to hold on to my desk if I felt tension. I tried to do that in class but it didn’t help. I went to her a couple of times and then I just didn’t go back.

My mom and I sat down with all the teachers and explained my stuttering to them. The teachers told me I could develop a signal for them to pass me over if I wasn’t ready. They were understanding and that helped.

The biggest issues for me were presenting and talking on the phone. Those became the two situations that I really tried to avoid, but otherwise I was okay. I would have conversations with the teachers and really plan how I was going to say things and structured my presentations to have more visuals. If I joined a group, I made sure I would do the least amount of speaking or I would volunteer to write the whole presentation rather than speak. My primary goal was ‘how can I not talk?’

College was a horrible transition. I found it hard to do adult things like calling my own dentist and advocating for myself. I would call my mom and cry. She contacted the clinical supervisor in a local university speech pathology program, and I started therapy there. For two years I was in and out of the clinic and I was a client of various graduate students. All of their therapies were fluency-shaping therapies so I felt like if I would just do it long enough, I would get it.

**“I never used the techniques, just my own way of hiding it.”**

I felt better about myself because of the accepting environment but a lot of the things I was doing in therapy I couldn’t do outside of therapy. I never used the techniques, just my own way of hiding it. I was doing what I always did, changing words, avoiding—

but I felt safe and accepted in the clinic setting. It was the only place where they knew my secret and I could tell them what I was feeling. They would listen and introduce me to other people who were like me. I did feel safe. The therapy never worked, but I kept hoping that if I just did it long enough it would click.

This was when I became interested in speech pathology and started down that road. I felt proud that the graduate students were learning from me. It was the only place I could take forever to say something, and they waited for me. I didn’t feel like I needed to cover it up. I could just be. So I started my major in speech and hearing sciences. I didn’t have therapy throughout that period. I thought I had everything under control.

Then I started grad school. That was a nightmare—it blew up in my face. I could not talk. How was I going to do this program? I thought about dropping out—it was that bad. I didn’t know

what I was doing or why I was doing it. My supervisor tried to help me with more fluency shaping strategies but that wasn't very helpful.

**A turning point:**

It was around that time that I was connected with a speech therapist who specialized in avoidance reduction. I don't know where my life would be if this hadn't happened. The first three months of therapy, I felt this weight lifted off my shoulders. I felt free—this knot stuck in my throat was gone and I could just stutter. I could just be myself and talk the way I talk. I wish I had been introduced to the idea of avoidance reduction when I was 14 because that's when I struggled a lot.

I've been a practicing speech therapist for eight years. I now do avoidance reduction therapy with my own clients. The youngest is in second grade and the oldest is in sixth grade. I teach them to become their own therapist, how to develop their own goals, and most importantly, that stuttering is okay. I help them create presentations for their schools to educate others. I'm surprised and proud when they present, and they know a lot and come off really confident. I taught them that.

I also help parents let go of the focus on fixing the stutter.”

*Ben, age 42*

“When it comes to speech therapists, some of them are good and some of them, well, they just don't know what to do. They have maybe a few courses and no education except speech techniques. It just doesn't work. I get it that everybody is different but when I was younger, I had a couple of speech therapists and some of them I liked and some I didn't. It just wasn't working, it was kind of boring, and I just didn't want to do it.

When I went to high school, I got a new speech therapist and what he did was so different. Typically, when it comes to speech therapists, they give you a book or a little note card and say, ‘okay, say this now, break it down,’ With this new therapist, we just sat there every day and talked. Mostly I talked and he listened.

I'm not sure if he did that for everybody but he did it with me. We just talked. It wasn't like a task or a tour I had to go on or whatever. I actually liked it. At the time I maybe didn't appreciate it as much as I do now when I look back at it at the age of 42. I definitely appreciate it now.

**With this new therapist,  
we just sat there every  
day and talked. I  
actually liked it.**

Now when I meet somebody who stutters, I just let them talk and be themselves. If it takes them five minutes or five hours or a day, I just sit there and listen. I tell them to take their time and say whatever they have to say. I'm not going to mock them or make fun of them. I'm not going to make a sly comment about their stuttering or poke fun at it. I'm going to treat them like I hope I'd be treated in return.

The other key is to be around positive people. When it comes to friends, family member, or school, be around positive people. I was so amazed when I got to high school and this guy, this speech therapist, did it so differently. Like I said, most therapists just gave me cue cards and had me say it again. This one let me talk and he never pointed out my stutter. He let me be myself. He was a really positive person and I do appreciate that.

I would tell parents to let their child know that there is nothing wrong with them. Let them know they are not alone. It will be okay, and you'll go through this together. You'll be here to help them along the way. Let them know that they never ever ever should feel afraid to talk to you about it. Parents need to be honest and truthful. Don't be afraid. You need to be their corner. Not every therapist is going to be a good fit. For whatever reason so many of them really have very little background. I didn't really talk to my parents about it. It's kind of sad. I wish we could have talked about it more. I think they thought it might hurt my feelings. I think most parents really don't know what to do.

*Bradley, age 29*

“My current therapy is so different than what I had as a child. During that time, I saw around eight speech therapists with therapy being all focused on fluency using speech strategies with the exception of one therapist. I think she used more of a cognitive behavioral therapy (CBT) approach without really telling me what was going on. She would encourage me to stutter on purpose and I just figured it was another strategy. She said, “You, you, you, you, you should bounce on a lot of your words in order to to to stutter well.” I remember her drilling the idea of “I needed to learn to stutter better” into my head. Voluntary stuttering is an approach often incorporated into CBT-like therapies, but I was too young to understand what was going on. I just remember that it wasn’t like all the other therapies where I was instructed to stretch my vowels or talk like President Obama where you’re only supposed to say a few words at a time,

Another therapist focused on strong air flow, which on a physiological level made sense. She would have me sing and talk in singsong. This worked in a controlled environment, but it never worked in the real world.

As a kid, I remember having an evaluation with a speech therapist who stuttered himself. He sat me down and he said, ‘you have a problem that’s never going to go away, so you have to figure out how to deal with it.’ His message was accurate, but it rubbed me the wrong way and I didn’t want to work with him. I think it should have been phrased in a more strategic and sensitive way.

I remember when I interviewed to get into a private school in the middle of high school. The guy who interviewed me had had a stutter. He had gone to this intense boot camp for a week and claims he was instantly cured. First of all, I’m calling bullshit on that, but okay. Instantly my mom became obsessed with the possibility... ‘we have to get you to that boot camp!’ I refused to go.

About four years ago, Mom heard about this guy who claimed to have ‘cracked a code’ and gave workshops that were astronomically expensive. She asked if I could give him a call and I was like, ‘Sure I’ll give this guy a call.’ I asked him about his clinical experience, and he said, ‘I don’t have any. ‘So wait. You want me to pay \$2,000 for your workshop and you’re telling me this will cure my stutter, but you don’t have any clinical background? What the hell is going on? Absolutely not!

As a young adult, I would go to therapy for three or four months and my speech would get better. It was expensive (insurance would never cover it) so I would quit therapy because I didn’t feel I needed it anymore. After a couple of months, the strategies would stop working. The therapists never took into account the holistic perspective and how everything is connected.

### **A turning point:**

I love my current therapy through the American Institute of Stuttering (AIS) because it’s a holistic way to treat stuttering. AIS uses an acceptance, avoidance reduction, and more cognitive approach. They’ve helped me to lean into my stutter instead of trying to avoid it using speech tools. My avoidance behaviors perpetuated disfluency and poor communication. Acceptance definitely contributed to decreased disfluency and improved communication.

I was always a very overt stutterer because my stutter was pretty significant to say the least. The hardest avoidance habit to break was that if I was having a hard time on a word, I'd immediately break eye contact. I didn't realize or understand that that was a defense mechanism that was perpetuating more disfluency. I realized this was something I'd have to work on. It was something that I could execute in the real world even if it was uncomfortable.

**“A more holistic, cognitive behavioral approach got me to a point of being truly okay with stuttering and I was able to stop my hardcore avoidance behaviors.”**

Another example of my current therapy is advertising. It's not something I was necessarily against, and I did it occasionally but not regularly. We did a lot of exercises where I would phone a store and say, 'hey, I have a question but before I ask my question, I just want to give you a heads up—I have a stutter. Can you be a little extra patient with me?'

Practicing that exercise helped me to develop an internal cognitive muscle memory and to be truly okay with it. I came to terms with the reality that using specific strategies in a controlled environment was not going to execute in the real world. A more holistic, cognitive behavioral approach got me to a point of being truly okay with stuttering and I was able to stop my hardcore avoidance behaviors. I was able to feel not just comfortable, but happy with how I speak.

Parents of kids who stutter feel like, 'hey, my child is different and I need to change this.' It is such a counter-productive approach. Furthering the narrative that everyone has to be the same is going to do so much damage to a child.

My parents are amazing people, and they would try anything they could to enable me to succeed but they also subscribe to this element of perfection. They want me to represent our family in a positive way and it almost becomes an obsession. It's at the point now where I've told my mom, 'I'm happy with how I speak. I'm a strong communicator. It's part of my brand.' She was extremely resistant but quite frankly, I have autonomy at this point.”

*Caius, age 31*

“My first speech therapist had no background in stuttering. I was put in an individualized educational program for speech delay when I was 32 months old. I was only saying four to six words at that age.

I continued speech therapy until I was a junior in high school. I pretty much changed therapists every year. Stuttering didn’t become an issue until 4<sup>th</sup> or 5<sup>th</sup> grade. I got on the bus, started a sentence, and finished it when I got to school.

In middle school I got a speech therapist who seemed more confident treating kids who stuttered. She would even get me a McDonald’s happy meal. She kept encouraging me and said I was doing better but I felt no carry over outside the clinic setting. It was very frustrating for me because I felt like I wasn’t using my tools correctly. It was my fault and it just made me feel worse. Looking back, they were trying to make me a fluent person when I’m a person who stutters so there’s a lot of incongruency there. The only way I could be fluent was to not talk so that’s what I ended up doing—avoiding all speaking situations in the classroom and at lunch. The therapy gave me hope at first but by the end it just discouraged me.

I had some speech impediments—a delay. My kindergarten teacher thought I was mute. I used to click my tongue rather than use words. In early speech therapy I was working on enunciation and pronunciation. I grew up where Portuguese was the first language, and the speech therapist told them they needed to speak in English so I lost my Portuguese.

I was absolutely not able to take the speech tools it outside the clinic. I felt dejected, isolated, depressed, angry, and frustrated. From 10 years old to 18, I was clinically depressed. It was my default normal. I didn’t realize until my mid 20’s that I had been clinically depressed. I would play video games to distract myself from the reality.

When I got to college, I started dropping classes where I had to do presentations and I was really struggling through the ones I had to do. I got to junior English, a required course to graduate, and the presentations were required. They were so struggled that I wanted to slide into a sinkhole. I had a countdown to the day of the presentation and continually stressed about it. I would wake up with anxiety and butterflies in my stomach.

The day of the presentation I woke up and I was literally choking on my stutter. I couldn’t breathe. When I got up in front of the room, I was sweating profusely through my shirt. I was holding my index cards and my palms were wet. After a few minutes of blocking, I just sat down. There was about five seconds of silence, then the professor said, ‘next student.’ I was so embarrassed. I was supposed to have a seven-minute presentation and I blocked for about two or

**“You CAN stutter and be smart and be a doctor and get married and do all the things that you ever wanted to do.”**

three minutes and then sat down. A couple of students walked by the desk asking if I wanted lunch. They were trying to be nice, but I said no. I went back to my dorm and laid down on my bed for about an hour.

**The turning point:**

When I got up and googled speech therapy on campus. There was a six-month waiting list and that’s when I was introduced to Vivian Sisskin and Avoidance Reduction Therapy (ART) through the University of

Maryland.

A big factor in my success is seeing the other people who have been through the therapy. You CAN stutter and be smart and be a doctor and get married and do all the things that you ever wanted to do.

So much of stuttering is the iceberg below the water. The issue with trying to be covert is that it leads to so much emotional distress. And now that I'm an open stutterer, I am much happier than I ever have been. The fluency has improved as a byproduct but so paradoxical because that wasn't the goal.

When I do stutter, it's tense for a couple of seconds and then I move on. If I'm trying to avoid stuttering, I will restart my sentences, close my eyes, try to start over, or change my words. It's just so much more mental effort and just leads to more effort and struggle."

*Cassie (also a speech therapist), mom to Austin, age 4*

“Austin was just over two when he started to stutter. I’m a speech therapist myself working in the schools. I was surprised and concerned so we immediately started applying indirect therapy—environmental changes—within our home. I already had kids who stuttered on my case load at school who were really impacted negatively by their earlier therapy. Had I not been in this field, I would not have known what to look for and how to advocate for him because I wouldn’t have known enough about it. I knew enough that I wasn’t just going to take him to early childhood or private practice and get any therapist who hardly knows anything about stuttering.

Once I had my second child, our first son went through a period of increased tension and he wasn’t sleeping very well. He was also starting to have prolongations. Prior to this it had always been just sound repetitions. He continued for about eight months—nothing changing. I consulted with several leaders in the field, both who did not recommend services, but to keep doing what we were doing. There was agreement that he was stuttering but he wasn’t showing any kind of struggle and no secondary characteristics. He loved to talk and was super verbal. We were directed to continue indirect therapy.

I was still concerned. Even though I’m in the field, I needed professional guidance. I wanted support on how to best support him. We had moved and were directed to the American Institute for Stuttering which focused on acceptance, avoidance reduction, and lots of parent counseling/coaching.

We started a parent coaching model where my husband, myself, and the new therapist, talked once a week. It was a phenomenal experience because it felt whole-body to me. The new therapist asked about emotional regulations, how we discipline him, how much outside time does he get, what are his routines? He helped us think about the whole picture if that makes sense.

The speech therapist didn’t have that many new suggestions apart from what we had already been doing but he provided validation and reassurance. Our son never even saw him. The speech therapist asked really thoughtful questions about communication scenarios and about our perceptions of Austin’s fluency and his transitions in times of stress. Having someone to talk to about talking—having that reflective talk, overall, helped us be more supportive in the strategies we were using.

It was ideal in a lot of ways. I feel very thankful for that. I was really surprised when our son became increasingly fluent. I told the speech therapist that I didn’t want to insult him, but ‘how did this happen? He was always mild to moderate, but never fluent. I thought it was here to stay and we were going to do all we could to support him.’ The speech therapist told us he thought all along it was a developmental stutter and it probably would have resolved without therapy, but there’s no way to know. Being able to find support for us as parents was so important and helpful.

*Charles, age 24*

“I started stuttering when I was five or six years old. Some of my first memories of stuttering were when I had difficulty reading out loud in front of the class. I started therapy when I was eight. Mom is also a speech therapist but doesn’t work with people who stutter. She reached out to one of her old professors and they did an evaluation. My speech rate was very high, so I went to speech therapy to speak slower. It kind of helped a bit—I don’t have a lot of good or bad memories.

At this point if I spoke slower, I would stutter less. After a while it didn’t work so I did more of a fluency shaping therapy, one-on-one, where I would get more relaxed, practice easy onsets, those types of things. The goal was for me to speak fluently. I remember going through tests and they would count the words and decide what percent of the time I stuttered. The therapy helped at first, then after a few months out of therapy something would come up and I would start to stutter again. This was middle school through high school.

In lower-feared situations with parents or good friends, stuttering wasn’t a big problem. Outside of that I was still trying to hide it at all costs. When I was in big crowds or meeting new people or had to do a presentation I would use a lot of tricks, switching words around, and pauses. It was a very frustrating experience because I could be fluent. I wouldn’t know why or when or how but I would start stuttering more and it was getting worse over time. I didn’t know much about stuttering causes, and I thought it would go away with time. There’s not a lot of education around the whole topic except for fluency-shaping. ‘Don’t stutter!’ Those were my messages as a kid growing up.

Definitely in terms of school, I remember my grades were pretty good, but teachers’ comments were that I was quiet in class and didn’t participate as much. I was taking a hit in the classes where participating counted. I wasn’t going to tell my teacher, ‘Oh by the way, I stutter.’ I never thought to do this. I definitely did not participate as much in the classroom setting. It would have been nice if I could have felt more comfortable participating. There were many times when I knew the answer, but I didn’t want to speak up, so it affected my grades.

I was a group leader in Boy Scouts so in a way it didn’t hold me back too much outside of the classroom. I played soccer and was the captain my senior year. I played ultimate frisbee and was the captain and did a lot of talking there but in the classroom it was hard. One of the benefits of these activities was that I was put into situations where there was a little more pressure and it pushed me to interact with a lot of other people. I don’t know that it had a massive positive or negative impact on my stutter—but the quality of life? Yes! It definitely improved my quality of life because I loved playing sports in high school and college and going camping and hikes and other fun activities.

### **The turning point:**

I was first introduced to Vivian Sisskin and Avoidance Reduction Therapy (ART) in college. I thought the speech therapist was crazy. All my life I had been told I had to hide my stutter and it’s taboo. Her entire therapy was about not using tricks and openly stuttering to advertise to other people. It’s been six years and I’m very glad I found this therapy. It

**“I do presentations. I stutter. I have no fear of stuttering. Nobody is laughing.”**

changed my life. I'm doing things that I never thought I would have done. I'm in medical school now. When I did my medical school applications, I included a paragraph about stuttering because it's a part of who I am. Then I went back and wrote the whole letter about stuttering after being advised by a friend's mom who is a writer.

I do presentations. I stutter. I have no fear of stuttering. Nobody is laughing. I would have liked to have done ART early on in life. It would have made my life a lot easier in terms of my speech and communication.

Whatever type of therapy you engage in, there needs to be more emphasis on 'it's okay to stutter.' Even though my mom's a speech therapist and my parents were very supportive, no one ever told me it's okay to stutter. That's one message I wish I had heard growing up."

*Chloe, age 25 (daughter to Janet)*

“I have an early memory around second grade about something being off with my speech, but I don’t remember if I was stuttering or not talking because of my stuttering. I saw a couple of different therapists that were about fluency shaping and fixing it. I didn’t like group therapy because I didn’t like hearing someone else stutter. Do I sound like that? I didn’t want to identify as someone who had a stutter. I didn’t want to relate to others who stuttered.

The next memory is late middle school. I got pulled out of school to see a speech therapist—it was definitely a fluency-shaping therapy. Weird exercises, take a deep breath, vocal stuff—there was one point where she massaged my throat. She put on gloves, got lotion, and had me talk. I kind of looked forward to it because it was relaxing and the lotion smelled good. But I look back and think, ‘what were they doing? Who would think that would fix my stutter?’

I stopped seeing her but saw two more speech therapists at that same office. More fluency shaping but not the weird exercises. Only taking a deep breath and exhaling and counting as high as I could. I could count pretty high by the end but I’m not sure how much that helped my stutter. After that, I would just talk. She would have me read and tell her about my day. She would count the stutters that I had. It was good when I only had a couple of stutters. It didn’t work long-term. I went two times a week, then one time a week, then every so often. Eventually I had to go back to two times a week because it did not stick.

**I only felt good when I didn’t stutter and that really didn’t stick.**

The whole time I was in these therapies I hated telling people why I went. I didn’t like telling my parents about my therapy or talking about my speech in general. I felt like speech therapy worked temporarily but it didn’t do anything to change anything internally. I only felt good when I didn’t stutter and that really didn’t stick.

### **A turning point:**

In college I heard about the group dynamic and Avoidance Reduction Therapy (ART). At first, I didn’t want to be in a room with other people who stuttered and hear them and be judged by them. It took me awhile to buy into it—peeling away tricks, showing my stutter to feel more comfortable. Early on a guy in the group walked up to me, made eye contact, and stood there and got it out and it seemed like he didn’t care. I remember thinking, ‘that would be cool if I could not care about my stutter.’

I think it would have been really great to have been introduced to ART earlier. The reason I wanted to cure my stutter was to not feel negative about it but if I don’t feel negative about it then I don’t have to want to cure it.

The feelings I had were worse than the stutter—way worse. I had all of these tricks to try to not stutter, but the tricks made it so much more noticeable and prominent. Now if I just let myself stutter, it’s quicker, it’s not as tense, I don’t feel as bad about it, and I’ve learned the people don’t care if you stutter. No one really cares. If I had come to that realization in my teens, it would have been a lot better. I would not have had as much anxiety about presentations, about meeting new people in groups and parties and things like that.

You need to get more kids into the ART experience. There needs to be more out there about why the ART approach is better for kids mentally. Up and coming speech therapists are still being taught fluency shaping. We need to stop preaching that. We need to talk about the different kinds of speech therapy. There's not enough backbone for this type of speech therapy to be pulled into the curriculum. I think in time it will be better but hopefully we can speed it up.

The older I get, the closer I am to having kids, the more I think about how I would react if my kid developed a disorder of any sort. I would feel scared and clueless and overwhelmed with trying to figure out what the best solution is for them. Educate the parents—that's a really big start. Children are not old enough or informed enough to know how to handle their stutter. I like the motto, 'it's okay to stutter' but I wish there were more resources for parents to give their kids about stuttering positivity and a kind of speech therapy you can go to that supports that. If the kid still wants to fix their stutter when they're 28, well, that's a shame, but they're old enough. It's a long journey to get to the point of 'it's okay to stutter.' It would be nice if the journey was shorter, and the kids could experience that earlier on."

*Constance, mom to Kyle, age 33*

“Our experience with speech therapy through the school system was very limited. We did some neuro-testing and our son was diagnosed with ADHD. We held off on meds but finally tried it for less than a week because it was clear it did not agree with him—and that’s when he started to stutter. I did not notice he had stuttered before that.

It was never terribly disruptive for him. We got 504 accommodations in 5<sup>th</sup> grade. They recommended speech therapy, and he went to a few sessions but he did not want to be involved and wasn’t practicing his tools. We brought it up again in middle school and he declined. He didn’t want to be different or pulled out of class. The stuttering was intermittent. I felt therapy was something he had to buy into to make a difference. Even those who are motivated can’t always use the tools. He just wanted to play sports and fit in.

He’s my oldest, he’s my first. All we knew was to throw resources at him. With the ADHD diagnosis, the stutter was sort of in the background—it came and went. As parents you want to try. In our son’s case, he came around as an adult and joined a support group focused on avoidance reduction and got more out of it then. He’s in sales and he owns his stutter. I’m proud of him and happy that he’s made peace with it.”

*Cora, mom to Harper, age 5*

“Harper just turned five. She started speaking fine when she was two and then the stutter started. It was really bad, very extreme. We started speech therapy at two and one-half and continued up until a couple of months ago.

As far as I knew at the beginning, Lidcombe was the only thing out there. The first speech therapist didn’t have any experience with stuttering and was using Lidcombe text-book wise. I was doing Lidcombe all the time, every day—taking 15 minutes for special time and catching her throughout the day—“oh, that’s smooth talking.” Two plus years of doing speech therapy every week and by this time I was so tired of it. We mostly did Lidcombe and went through five speech therapists. The last one finally acknowledged that Lidcombe wasn’t working. I could only say “smooth talking” so many times. It was getting hard on my mental health as well.

Under the advice of a new therapist, we tried another method—trying to get her to talk robotically. I can’t make her talk like a robot. It was a battle, and she would not do it. Fifteen minutes a day she was supposed to talk robot. It wasn’t good for either one of us.

Then I find out that a speech therapist can know nothing about stuttering. You want the best for them, and the professionals mean well. All the information is so conflicting and there’s no one to turn to. The family doctor says the only hope is speech therapy. Been there—didn’t help.

Since I just totally stopped everything to do with speech and language therapy, her speech seems to have gotten better. My husband and I were just talking about it—it seems like there’s less stress. You’re the first person I’ve talked to who has given me a different perspective and told me about other options. I say to myself, ‘accept the way she is, this is the way she’s going to be.’”

*Courtney, age 41 (daughter of Linda and John)*

“I remember home movies of me—Dad encouraging me to ‘sing your ABCs.’ I got to R, and you could see I was going to stutter. I started to block and my dad yelled ‘R’ from behind the camera and you could see on my face how sad I was that my dad thought I didn’t know. I just walked off—I couldn’t say anything about it.

In elementary school I did not want to stutter. My parents found the stuttering specialist lady with the best advertising around and hence began a five-year quest for fluency, aka, reign of terror. The therapist had developed a technology that involved wearing an accordion belt to practice diaphragmatic breathing. The belt was connected to computer games. Tarzan and Jane were trying to get across a ravine on a rope swing. If I used my fluency tools and didn’t stutter, Jane would get to the other side of the ravine. After saving Jane using my fluency tools, I’d walk outside and couldn’t talk to my own mom without stuttering.

I figured I just needed more time and practice.

In second grade we got to bring in our favorite book to school and each have a turn in the teacher’s rocking chair. I was excited because I really liked my book. I got in the chair and I’m sure I blocked a lot and held back. I was never excited about a turn in the teacher’s rocking chair again. I remember telling my parents about it and heard my mom crying to my dad that night. I thought, ‘I can’t make them sad; I won’t talk about that to them.’ She didn’t realize I could hear.

I had mental health issues tied to the speech therapy because I was trying to be a different person and the therapy fueled that effort.

The message is ‘aim for fluency and until you achieve fluency, you’re not good enough.’ That became my own narrative, and no one challenged that—they just fed it. There was never any explanation as to why someone who went so long and did so much homework, (and whose parents paid so much) was not having the purported outcomes. That was never really addressed so I was left to think it was my fault.

I interviewed for my first professional job never showing my stutter and it was a disaster. It was all I thought about—I wasn’t living well at all. I was super stressed and anxious. I was stifling myself and freaking out.

**A turning point:**

Fortunately, my mom didn’t give up. She found Vivian Sisskin at The University of Maryland—a local university, and this therapist had a different approach. She focused on avoidance reduction instead of fluency. This focus helped me get out of the box I had painted myself into.

Now I’m finding tons of support just being involved in the stuttering community and group therapy. I admit I went for about a year before I let the group hear me stutter. I have now been able to ameliorate the damage from childhood. I don’t know where I would be without having done that group and that work. The stigma felt like fact to me. ‘I’m not okay so I’ll just be quiet.’”

*Cyrus, age 44*

“There’s a pre-iceberg\* stuttering kid and the post-iceberg stuttering kid. For me I don’t remember caring until I was around 10. Then it took over my life. It went from a non-issue to everything—fast. That was my transition from having no or very little stuttering iceberg to have a big iceberg.

I went to universities and Hollins and all sorts of programs. In retrospect, I thought it was about chasing fluency but it’s really about quality of life. That’s what matters. We need to learn not to hide, to come out of the closet, not be trying to fool people. It’s a miserable way to live.

The therapy that worked was when the therapist took me around campus and made me look others in the eye. Everything in my being didn’t want to look at the person’s reaction when I started stuttering. My whole life had been about hiding my stutter.

What makes us human is our relationship with others, talking to other people. I was given the message in my childhood speech therapy that I couldn’t do that with a stutter. The therapist showed me some variation of easy onset and would tell me to go out and practice every day. I’d always be able to do it in the therapy session and by the end of the session I would think, ‘maybe it will stick this time since it was so easy with the therapist.’ It never did. It would just fall apart. The speech therapist wanted to give me confidence and be positive about my chances so he was telling me that it should work. I ended up thinking, ‘am I doing it wrong? Am I a slacker? What’s wrong with me?’ I didn’t know at the time that this wasn’t working for other kids either. To this day, I haven’t met anyone for whom this worked.

There was a total lack of understanding that just because it was working with the therapist, it would work everywhere. They measured it on their little thing. ‘When you came to us you were stuttering a lot and now you’re hardly stuttering at all.’ I would never want to make them feel bad, so I didn’t tell them it didn’t work outside those walls. I was a kid; I didn’t want to open up about how much this was hurting me and dominating my life. All the effort they were putting in and it wasn’t helping. I felt guilty and ashamed. I wish I had had the therapist when I was a kid that I had in college. He was all about desensitization. I wished someone would have done this for me much earlier.

I never had any clue what was happening when I stutter. I knew it seemed to be related to who is listening or not listening. Even though I was confident, I would stutter significantly more on gradations of the person I was talking to. Someone I knew vs. a stranger, etc. Stuttering is holding back. How do I physically put myself in a position to stop holding back. I would suspect that the more a child learns to dislike their stutter, the more sensitive they are about it, the less likely they are to outgrow it. That performance anxiety builds up. Not focusing on a fix is so counter intuitive for parents, especially when the experts say a focus on fixing is evidence-based.”

\*<https://www.stutteringhelp.org/blog/sheehan-stuttering-analogy>

*Drew, age 21*

“While I was in elementary school, a lot of the focus was on fluency shaping and trying to do slow speech and things like that. The therapy was through the school system. At first the school system didn’t want me to see a school speech therapist because I was doing too well in school, and I didn’t qualify to get an individualized education plan. Mom and Dad fought to get speech therapy services and somehow won.

I felt like I was dumb when I couldn’t use the techniques. I knew what I should be doing but it didn’t generalize out into lunch time and when I was just talking to kids or my teacher. I didn’t know why I wasn’t fluent. Why wasn’t it helping? It was confusing. I didn’t want to go to speech therapy because I was doing everything I was told, and it wasn’t helping.

In elementary school I was engaged and would speak in class. When I transitioned to middle and high school, I became more self-conscious about it and the speech techniques were not working. That was when I began to raise my hand less and speak less. I was somewhat lucky in that I was always talkative in a social setting, just not when I was in class. I wasn’t volunteering to say things when I did know the answer.

I knew why I was going to speech, but the speech therapist never specifically said why. I knew that I would get stuck on sounds, but she never sat down and said “you see me because you stutter” so that wasn’t really something I thought about a whole lot. My mom and dad would say that, but not the speech therapist. I don’t think she was very confident with someone who stutters. I don’t remember anything of value and she didn’t focus on the social and emotional side of things and that was also something that made it challenging. I was doing well in school, was well-liked, and I liked to talk, so I checked off all the boxes of someone who was fine.

My mom has since told me that she was talking to the school speech therapist and that mom suggested that she and I should talk to the class about stuttering because she had seen that was something some kids found helpful. Mom thought that made sense, but the speech therapist was like, noooooo. It doesn’t seem like she knew enough about it. I don’t know why she didn’t want us to do that.

My mom went out and found a speech therapist who specialized in stuttering (American Speech, Hearing, Language Association’s Board Recognized Specialization in Fluency – BRS-F) and got that person to come in and talk to the speech therapists at the school. The BRS-F therapist was quite good, but Mom said the body language of the school speech therapists made it seem like they didn’t want to listen and the BRS-F therapist was a waste of time. There are a lot of speech therapists who do not know a lot about stuttering.

I grew increasingly uncomfortable with fluency shaping and speech therapy with the goal of trying to become as fluent as possible. I had done fluency shaping for so long and it was like I know what I should be doing, it’s not that I don’t know the techniques, I do, if it was that simple I would just constantly do them and feel totally fluent but that’s obviously not the case. It’s not that simple. If I just like slow down and think about what I’m going to say and pause—obviously it’s not that simple. Those can sometimes be helpful but not necessarily with the goal –f becoming fluent.

**The turning point:**

In the summer of 2016, I met Vivian Sissken who did avoidance reduction therapy (ART). She explained that she wasn't going to do fluency and instead would engage in a special kind of speech therapy focused on avoiding avoidance. I thought—this lady is full of shit, she has no clue. Turns out that was the best therapy I had. ART focuses on speaking spontaneously, saying what you want to say and not doing speech tools. Focusing on feelings and emotions earlier would have been more helpful. We didn't focus on the emotional side of things. It should have been a main component of the therapy.

**“Focusing on feelings and emotions earlier would have been more helpful.”**

Right now, I'm a junior in college with a double major in speech and psychology. I obviously found the field of speech therapy because I'm a person who stutters. I've seen a good number of speech therapists, some who did a good job and some who did not do a good job. That's what led me to the field.

*Dwight, age 25*

“I’m told I started stuttering when I was two. My first conscious memory was probably from therapy—those are kind of confusing memories. I didn’t understand why I was there. It was a lot of little exercises. The ones that stand out the most are when they recorded me and I heard it back. I remember the first time hearing my voice played back. Who likes hearing their own voice?”

For the most part I was very lucky. I didn’t have any bullies or anyone making fun of me. If it did happen, it was a small thing with people I didn’t really know. The negative impact was a bit more insidious—just not talking and not saying what I wanted to say and feeling like when I did say something, it wasn’t right. This happened a lot in a classroom environment when everyone is going around saying what they did or their name. That’s the clearest one I remember having anxiety over—going around to “tell one thing that we found.” I would not be able to get that out or I’d butcher it just to get it out. I’d think, ‘That’s not what I really wanted to say at all!’

That still happens—where I’ll say something whether it be replacing words or just getting so anxious about stuttering that I stop paying attention to what I’m saying. I’ll think, ‘I didn’t want to say that! It not only sounded bad, but it was just wrong!’ What are you going to do? Five minutes later say ‘hey guys, you know that thing I said five seconds ago, that was just wrong. I wasn’t a lie; it just wasn’t quite right.’ Then people think I’m this other person who doesn’t say what he means—I get into these self-talk spaces.

The idea that I didn’t talk right was definitely a thought in my head and it is still a thought in my head. It blossomed during those times in therapy as a young kid. It took root, it bore fruit and left a big impact. The therapists I saw did not help me address my feelings and get out in front of that. I think I could have really benefitted from that as a kid—to talk about those feelings in a concentrated effort, a repeating regular fashion. I don’t remember ever talking to a therapist about that—well in the sense of “oh, do you feel a little bit bad when you stutter sometimes?” Sort of talking down. Kids see right through that—that type of voice. It might work with a two-year old, but if they have the ability to understanding your words, they have the ability to understand your tone. Kids know when they’re not being taken seriously in therapy.

**“The idea that I didn’t talk right blossomed during those times in therapy as a young kid. It took root, bore fruit, and left a big impact.”**

When I was around six, I remember being told by a speech therapist to expect questions, which I thought was a good thing—to not balk or get angry, just to understand that people don’t understand. She told me to describe my stutter as ‘a hammer on the vocal cords.’ I don’t remember them telling me why it was happening so I only had these weird images about a hammer on the vocal cords. I didn’t have a vocabulary to talk about what I was going through.

### **A turning point:**

We stopped traditional therapy when I was around nine, but as a teenager, I attended group sessions at a local college. These sessions were facilitated by a rather unorthodox speech professor and included others who stuttered and students of speech therapy. This really helped me to practice articulating my experience and developing a vocabulary around it. This was a

place where I could talk about it openly. Practice in talking about it—that was the main thing that gave me the words.

I loved going to those sessions. I was an expert. Anything I said about it was valid. There wasn't a way I could get an answer wrong unless I actively lied. It was a space where I was totally free to just be open. It was a space where that was rewarded, a space where that felt helpful for other people too. And I felt like I was helping other people. It was great for confidence—to be able to talk to a group of adults, mostly young adults, but still adults, and have some authority—some expertise, something that I could offer. It was a space where I wanted to talk. And that was really fun. Every time I went, I just exhausted myself talking.

That experience impacted my college years quite a bit. Talking in front of a bunch of people—and the practice doing that—being able to remember a time when doing that was comfortable and fun. There was no stress. It's like it gave me muscle memory of having done that at least once—that was good.

I think parents are in a tough position. For instance, if a kid is doing a presentation in school, they need to be allowed to feel what they feel if they do stutter and/or block. It doesn't help to tell the kid “You should feel good about it” because they're not going to. Maybe explain that it's good that they tried. Ask them how they're feeling about the speech—what they're thinking about it? Let them bring up the stutter if they want to talk about it. You don't have to drag that topic out of them.

Honesty is one of the more powerful things you can have in your speech and your emotions. Your stutter doesn't have to, in anyway, undermine your honesty. Getting up there is practice no matter how it goes—and you learn from it. You're not going to learn if you succeed every time you do something. Whatever happens, you can take what happens and learn from it.

It's hard for parents. It's hard for kids. It takes a while to get the right words for it and so I feel like that's a good reason to have it be told to a person who's not emotionally involved first like a therapist. A kid can get exercise in saying it a way that's truthful for them before they bring it up to a parent who is stressed and worried and is going to have a desire to react and to fix things right away.

That's another thing—the most important thing you can do is make sure there's an open line of communication with the kid. Talking to your kid about this weird thing that neither of you have experience with—it's not going to be perfect. There may be some little hiccups—some big hiccups—along the way. Your child may not be receptive, you may feel like you said something ‘wrong,’ but if you have an open line of communication, there isn't anything you're going to say with good intentions that can't be readdressed. If your attempt to talk about it fails once, it's not that big of a deal because, in the long run, you're hopefully going to have mostly successes. They need to know that door is open.”

*Eliza, mom to Marcus, age 10*

“One day our son had woken up at 4 a.m. and consequently was exhausted at school. He was a late July birthday, so he had just turned 4 and got stuck in afternoon 4-K (kindergarten for 4-year-olds). His stuttering was so bad in class he couldn’t get a word out and his teacher felt we needed to refer to speech services. We had not noticed it at home or any place we took our son.

Being a teacher myself, it was hard to hear something was wrong with our child, but we wanted to get him help even though we were still not noticing his stutter at home. As the year wore on, we noticed it more and more and it was no longer just a school problem. At first it was only when he talked to strangers, but then it was when he was talking to everyone. By the time he hit third grade he started to develop secondary behaviors.

We had a poster in his room with turtle talk, take a deep breath—all these visuals of what he was supposed to do before he opened his mouth. My instinct was ‘why do this?’ I didn’t think that laying it on him thicker at home was going to help him. We made a little bit of effort at home, but we left most of it for his therapy at school.

By the time he was in 4<sup>th</sup> grade (last year) he was pulling his ear and jerking back his head when he was speaking. The speech therapist would always talk about his percent of syllables stuttered and the number of times he spoke incorrectly. At individualized educational plan conferences, they would say, right in front of him, that he needed to just remember to use his strategies. I remember feeling uncomfortable with that—but giving her the benefit of the doubt as a professional.

**A turning point:**

**“Our goal was wanting him to feel confident speaking.”**

Last fall I overheard a woman talking about a presentation she attended by another speech therapist who had a different approach. I reached out to him, and he told me about your book. My husband and I both got the book and read it right away—it was a big ‘a-ha’

moment. This new speech therapist met us at a coffee shop and told us his story. It aligned with what was going on with our son and he talked us through how to advocate for our son. Our goal was wanting him to feel confident speaking. He advised us to bring that goal to the speech therapist at school. Coincidentally, as an educator, I have been working on social emotional learning and I developed a survey for our son to take. It was heartbreaking—how little confidence he had in himself as a communicator.

I told the school speech therapist that I would love to continue services if we could just focus on building his confidence. She said she needed to ask her boss. A week later she said, ‘my pupil services director won’t allow me to do these kind of services because it’s not speech therapy—it’s not the practices that we are supposed to be using.’ ‘Really?’ I asked her, ‘Isn’t the goal of speech therapy to help the child feel confident of their speech?’ She said the whole purpose doesn’t matter, that she needed to use the techniques she learned in college and in reading. I had learned so much from the other speech therapist and understood more about the lack of expertise. She did not know of or want to admit the potential damage she had caused. We pulled him from services and within a couple of weeks his secondary behaviors stopped. Since then, we have just been letting him be a kid. We’ve been managing far better on our own than with the therapy we were getting in our school district. It’s not therapy if it’s not working.

As a parent I had no experience or background with speech therapy in general, especially in fluency. I knew nothing. You don't know what you don't know. I would have liked to have had a choice of resources and information on the harm that can be done.

I reached out to the speech therapists in my district, and they had never heard about different strategies—they had not heard of your book. It's heartbreaking when I think of more kids out there going through what our son went through. I really wonder if he had just been left to be a kid, would he be part of the 80% who see the behavior subside by the time they're seven? Is it possible the therapy prolonged it?"

*Eric, age 19 (son to Faye)*

I can only remember bits and bobs because I was younger. My mom and dad realized I had a stammer when I was five and they took me to speech therapy. I did that for quite a long time. The SLTs tried to show me techniques to help me control the stammer. They tried to get me to slide my words. I thought speech therapy made my stammer more noticeable. It made it more obvious. They showed me breathing techniques that helped a bit but other aspects that didn't help much.

Therapy showed me different options and ways to dealing with my stutter. Breathing techniques, take a deep breath, think about what I was going to say— there were a few more. The breathing is what I focused on the most. I hated drawing out, sliding in, all of that.

**“I thought speech therapy made my stammer more noticeable.”**

**The turning point:**

In speech therapy they were teaching techniques to try and fix my stammer. When I came out of therapy, I had to learn myself that the techniques are there to help but I can't be fixed. Once I embraced it and accepted it, things started getting easier.

Embracing it worked more than the guidance we were getting from speech therapy. Occasionally if I'm tired, I have a little bit of it, but it's still not really noticeable. I don't really stammer that *much anymore*.

*Faye, mom to Eric, age 19*

“Eric’s nursery school initially picked up his stammer at age 3 ½ and referred him to be assessed by child health. The referral took forever, and he was eventually seen when he moved to his primary school just before he was five. They had a few sessions with him in school and observed him in class and at play. We were then invited to a meeting where they told us he wasn’t stammering in class or with his friends so it must be a problem at home! I remember this conversation like it was yesterday. She really made us believe it was something that we were doing to cause his stammer. He progressively got worse; however, we were reluctant to go back to school as they had made us feel like it was somehow our fault.

Both my husband and I were very anxious, and we wanted to fix our son. Something was faulty with our child, and I wanted to make him perfect. It was such a wrong thing to do, with hindsight—we wanted to exhaust every option we could. Eric was bullied at school, often in tears and asking me to take him for an operation to have the stammer removed. We felt so much pressure as his parents. We had the impression that there was therapy that could fix the stammer.

When he was seven, our general practitioner referred us to the National Health System local speech and language team. He was finally given an assessment when he was eight and by that time his stammering was quite bad. He was getting bullied at school and his confidence and esteem were very low. From his assessment he then had weekly sessions with us also involved. The focus was on his fluency and slow speaking through play mainly. I remember he got maybe four or five different speech therapists so there was no consistency in the therapy and no chance to build a therapeutic relationship. The therapy was very repetitive, and progress was slow. They talked at him, and we were not involved at all. They wanted him to slide his words and stuff. He went for so many appointments and I now know he hated every moment of it.

**A turning point:**

I researched other support and eventually got a refer to The Palin Centre for Stammering and their parent-child interaction therapy was outstanding. They focused more holistically and looked at his mood, anxiety, and self-esteem. They also gave us, as his parents, educational days on our anxieties surrounding his stammer. They provided him with a group outdoor pursuits week with several other kids who stammered, and he returned a totally different kid. Before this therapy, the speech therapists didn’t recognize the damage they were doing.

**“They focused on helping you help your kid build their self-esteem.”**

Eric still stammers some days worse than others, but he has his public service degree and is now studying for his nursing degree. Nothing phases him, nothing holds him back and his confidence goes from strength to strength.”

*Francis, mom to Paul, age 21*

**No turning point needed:**

“My first exposure to stuttering shaped the way I took it in, felt it, and viewed it. My sister, who is eight years older than me, had a very severe stutter. My baby book looks like I showed signs of stuttering around six or seven. In the classroom, when the teacher called on me, I couldn’t talk. Speech therapy was all about suppression. ‘Why don’t you try saying it like this, breathing, exhale.’ I couldn’t understand what I was supposed to be doing. There was no way to practice. No one asked, how do you feel? I was switching my words around—still am. Don’t even realize I’m doing it. I don’t make sense sometimes. I’ve shaped my life to avoid having stuttering moments.

Then my son Paul comes along. His kindergarten teacher said, ‘I think he’s stuttering—if you intervene now, you can do something about it.’ It was our good fortune to engage with Vivian Sisskin, a speech therapist who didn’t follow that train of thought. Her therapy focused on avoidance reduction rather than fixing the stutter. The stutter came and went. It wasn’t until he was in ninth grade that it really began to impact him. He didn’t want to go to school, he’d hide in the bathroom, his grades tanked, his self-esteem tanked. Vivian connected our son with a young speech therapist from her practice who had a very can-do kind of tomboy personality, perfect for Paul. She was positive, friendly, and relaxed.

**“He used to be quiet, even around family. Now he's right in there and he's a listener.”**

Paul is a big soccer player and sings in an acapella group. One of the first things this therapist started working on was not about fluency-shaping at all. He’d come home saying things like, “you know mom, you can’t control what other people think but you can control what you think about yourself.”

Then he started doing group therapy which gave him exposure to a range of young adults, all different. He used to be quiet, even around family. Now he’s right in there and he’s a listener. He’s the most emotionally intelligent one there is.

Is it always great? No. He can tell you—he’s interviewing for jobs right now and he had to have a Zoom interview and he stuttered more than he usually does. You’re wondering what people are thinking. You’re seeing horror, confusion, pity, even maybe disgust. He didn’t get that job and he felt it was because of his stuttering. That hurt as a parent. But I also feel he’s in a lot better shape than I was.

Parents need good psychological education about stuttering. They need help to restructure what they often think and feel. No one is supporting those domains of functioning that are so important to be a healthy person. Many people who stutter have a very successful life and find joy and meaning in their lives. This is what needs to be talked about especially with parents of young children.”

*Frank, age 52*

“My stutter began when I was five or six years old. Having to read out loud in class was bad. I worked with a speech therapist when I was younger and it kind of went away. They tried to get me to slow down and use soft entries. I was told to practice breathing from my stomach and not my chest and to relax the throat and shake my hands, that kind of stuff. That was the standard approach. This would have been around 1975. From the time I was eight through twelve, whatever they did for me worked quite well and led to my developing good avoidant skills like changing my words, using pauses and hums and ahhs. I don’t remember actual stuttering between the ages of like eight and 12.

At age 13, I went to a boarding school and my speech disintegrated. I saw a couple of different speech therapists and one who turned me around by 100%—just unbelievable approach. She did a lot of the same things that were done with me when I was younger, but she did it in a different way. It was like more of a conversation with her. She also had me read out loud for hours with her. When I got stuck on a word, she had a very kind way of coaching me through using some breathing and easy onset techniques. It got to a point where my fluency was not a problem at all.

I was pretty good for a lot of years, up until 20 to 21 and then I started to notice it coming up again. Some of the avoidance things I did, especially from 18 to 25, really made my speech worse like pauses and substitutions of words. I would screen my words in my head and substitute the words I thought I would get stuck on. Every sentence I said out loud, I had already put seconds worth of thought into, but nobody would ever pick up on that. My mum was fundamentally aware of my speech as most moms would be, but I did a very good job of hiding it from her.

I’ve been with the fire department for just over 27 years now and the radio work became a bit of a fear. The thought processes a stutterer goes through tend to make it a bigger problem than it needs to be. That’s what happened with me. I developed severe stress, anxiety, and depression. I started to medicate with the wrong stuff and booze became a bit of a concern. I’m lucky to have a supportive wife.

I had been to see various speech therapists in my adult years and some of them didn’t have any idea about how to treat a stutterer other than, ‘you’re going to do hours of practice every day and you’re going to stand in front of a mirror and you’re going to do deep breathing.’ To be honest, I was completely fed up, I became quite annoyed and angry.

**A turning point:**

Then somehow, I found out about a speech therapist who approached things differently. When I sat down in her office, I was angry, depressed, and anxious. I might have scared her a little bit. I said, ‘You don’t waste my time and I won’t waste yours. I do not want to be sitting here doing repetitious sounds and everything else under God’s green earth that you think might be necessary. So tell me about your approach.’

In her therapy, we touched a bit on my speech, but we mostly focused on the pent up frustration about having to manage my speech. I was exhausted from constantly feeling like I had to be in front of my speech.

She didn't really tell me what to do but there was a lot of counseling that went on, even dealing with some of the trauma from my job. At the end of the day, I found that my confidence was coming back, and the anxiety dropped off. We processed a lot of the social, psychological, and emotional baggage around my speech. We focused around the outside of the stutter rather than directly on the stutter. Once I started down that path, the stuttering started to get better. I've learned to be kind to myself. I can now stay out of that fight or flight state.

**"...parents need to understand that you need to look at the inputs because if you're only focused on the output, the stuttering, you're not going to help anybody."**

I've made gains with past therapies, but I would always slide back because I could not keep up that level of effort. After spending 40 years of my life stressing about my speech, thinking I'm being judged all the time, I can honestly say to you, 'I don't care.'

I think it's really important that parents understand that you need to look at the inputs because if you're only focused on the output, the stuttering, you're not going to help anybody. When this therapist asked me, 'what do you think made your stuttering better?' I said, 'I'm not sure I can tell you—maybe unloading and venting, processing through a lot of crap. I don't know what happened. It just went away.'

I can sit here right now and say to you, 'I still stutter,' but it's not about being a stutterer. It's about how I feel about myself and I feel great! I don't need to be 100% fluent in order to feel good about myself."

*Helena, mom to Lukas, age 17*

“Lukas has been in speech therapy since he was about four. Certain things have improved but for the most part I don’t see how it has really improved his speech all that much. He’s 17 now, so it’s been quite a few years.

He was about four when his preschool teacher brought it up to us. He’s our first so we didn’t realize that it was something to pay attention to or be concerned about. We just thought it was him learning to speak. We had him evaluated by a private speech therapist and she came to his daycare to work with him. How much cooperation you can get out of the child that young? When he went to kindergarten, he began speech with the public school system, and he’s been in speech ever since. We’ve asked him if he wanted to continue or if he would rather just drop it, but he still meets once a week with the speech therapist in school.

In the beginning, therapy was mostly about slowing down—the speech therapist called it turtle speech. She would focus on different sounds like his Z’s, an S’s. As far as the actual stutter, it was through the school system, and I don’t know that she had specific training for stuttering. It is very hard to find a speech therapist that specializes in stuttering. We had even thought about continuing private therapy sessions with someone who was more specialized, but he really didn’t want to do that. We don’t talk about it much anymore. After so many years, it’s part of who he is.

**“He’d goes stone-faced,  
and we have a hard time  
pulling him out of it.”**

It is difficult at times for him to speak and it has given him anxiety. He would get so nervous and frustrated that he would just completely shut down and wouldn’t speak. I’d get phone calls from the school telling me he wouldn’t talk, wouldn’t communicate. He’d goes stone-faced and we have a hard time pulling him out of it. It

was really affecting his schoolwork. That’s when we started seeing a therapist for anxiety, from the time he was in 3<sup>rd</sup> to 6<sup>th</sup> grade. He plateaued and we didn’t continue. We told him to let us know if there was ever a time he wanted to go again.

The school-based speech therapist does give me updates through his individualized educational plan. She hasn’t contacted me yet for this school year like they usually do in the beginning of the year just to go over things. I always stress to them that it’s still the stutter. Sometimes it’s not bad and then sometimes it’s very bad. For us, like for so many parents, there’s no rhyme or reason. You try and put your finger on why his speech was so challenging in that specific time and you just don’t know. They say it could be diet, it could be he needs more exercise, it could be vitamin deficiencies. Then I went through, ‘what did I do?’ You don’t know.

There are so many other great things about him that we focus on. Right now, he’s playing football with the high school team. He picked up guitar a few months ago, which has been good because it’s something that he can do on his own. He’s not very social. He likes doing things alone. I wonder if it’s tied into the whole speech thing, because he doesn’t have to communicate that much. Is it really a good thing for him to spend so much time alone, but now he does football every day and a guitar lesson once a week. He did jujitsu which he was great at, but he

dropped off doing that. I hope he'll get back to it one day. He does lack confidence. Anything that will help raise that is great.”

The goals of his school therapy have pretty much stayed the same. They use a lot of words and terminology that I don't always understand. When he reads, he is more fluent and when he talks in a lower voice, he's more fluent. When he gets nervous and excited, it comes out more.

I don't think speech therapy has done very much. I don't think it's hurting. I don't want too much focus to be on that he's talking wrong. I don't want that. I did ask him, 'would you rather just stop?' As of right now, he still goes, I think there's a group, at least one other boy, that that's with him.

When they're 17, they don't want to think about it. I don't want it to be the elephant in the room, but he doesn't express what's going on or if something is upsetting him. I wish he would open up a little bit more.

It is difficult for him to socialize and engage. You see people just having a conversation and you realize that's difficult for him. It shouldn't hold you back, but unfortunately people aren't educated about it. There should be more awareness. Most people are patient. He'll now order his own food when we're in a restaurant, which is great, because when he was younger, he wouldn't do that. If the waitress doesn't understand, he'll repeat it, so he works his way through it.

I saw him once today. He stayed home from school because he's not feeling well, and his nose was running. He came down for lunch and that was it. It's hard, you know? You think, 'should I intervene? Should I go down and engage him in conversation? Should I just let him sit down from the computer? What do I do? Are you okay in there?' It's a conundrum. As parents you don't want to see your child struggle with anything. You would cut your arms off to make it go away but it's not enough.”

*Holly, mom to Theo, age 10*

“It’s important to give parents the information that there’s more than one approach. Theo’s therapy all felt so prescribed. His first speech teacher didn’t have a lot of experience with kids who stutter. When we had a meeting, she said, ‘he can say all of his letters!’ I said ‘yup—but that’s not why he’s in this class.’ She didn’t have a clue as to his speech needs.

The next year (still pre-K) he had a new therapist and was in a class with one or two kids who stuttered. She mainly focused on speech tools—practicing how to say things, turtle talk, blow out a candle, etc. He would interact with other kids in small groups and she would observe and assess. This went on until kindergarten. In kindergarten, he continued speech therapy with a different therapist and she still focused on speech tools, not anything like what would you do if you got teased. His last therapist said she was going to do that, but it didn’t happen.

Theo did not like being pulled out of class for therapy. I don’t think he used his tools outside of therapy—he forgets them. When he’s talking, he doesn’t stop and use a speech tool. He’s very competitive and hates to lose. He gets upset if he gets a bad grade. He’s a perfectionist.

In third grade he switched schools and had a different speech teacher. That’s when he said he did not want to go anymore. “Mom, I talk just fine!” I was on the fence. Sometimes they would recommend that we remind him to use his speech tools, but we never did that. We were not going to highlight that he’s having an issue. He adapted—if he can’t say an ‘s’ word, he’ll pick a different word. Once he started getting older, what more could they have done for him? They were still doing the same thing—what else are you going to offer up?

During the pandemic and distance learning, he did speech at home one time a week over Zoom.

This was a Google meet with two other kids and he had to read a paragraph, purposely stutter, and then read it fluently. Then she would have him correct his stutter. Once again, he started to say ‘I hate speech, I don’t want to go.’ They had given me a sheet of speech tools. I brought it out and asked if he knew these and was going to use them and he said ‘no.’ He had no idea what they were. That’s when we pulled him out of speech therapy. The speech therapist sent

**“If anything, I think he’s speaking better since being pulled from therapy.”**

home a booklet that he could work at. I haven’t looked at it since. If anything, I think he’s speaking better since being pulled from therapy.

I didn’t know there was any other therapy than speech tools. I’m a teacher and I know it’s whatever the head of the special education department wants to do. Everyone needs to get the same service and it needs to be approved at the district level. A lot of it comes down to money. Maybe it would be helpful for him to learn those tools, but in a few years, not at eight years old.

The window of learning the speech tools is gone—it’s not like they’re teaching him different things each year. It’s the same thing. ‘If you have questions, let me know.’ I didn’t know what questions to ask and there was no proactive communication. His goals were that he should be at such and such percent of syllables stuttered by using speech tools. The goals were not connected to confidence in speaking, maintaining his level of conversation, gaining confidence to talk more, nothing like that.

I think sometimes it bothers him, but it's a fleeting second. He doesn't lay awake at night thinking about it. He is talking a mile a minute. He raises his hand in the classroom. He's a leader—he doesn't hang back. That's what I want him to continue. It's not wrong for him to stutter. It's not something we need to correct. It's managing it, helping him feel comfortable with it. We don't ask things like 'how was your stuttering today? Could you stop and say that more slowly?' We just don't make a big deal about it.

I had no idea that there were different types of therapy until now. You sign your child up, he qualifies for speech, this is what the program is, tada, tada, tada. Once he got to school it's like, 'thanks mom, we'll take it from here.' I felt sidelined. I'm glad we pulled him out."

*Jacklyn, mom to Brayden, age 13*

“The stuttering was driving us nuts. There was no selection process. I assumed since this was a professional speech therapist, they knew what they were doing. I had red flags at the beginning. The therapist told me that ‘If kids are stuttering at age seven, chances of stopping are very slim, but I think I can help him.’ I assumed she meant to help him be fluent. I didn’t press because I didn’t know there was anything else. All of the therapy was directed towards fluency, nothing beyond speech tools. There was no counseling for either Brayden or me.

We were getting to the point where—well, I couldn’t take it anymore. The stuttering! My husband—both of us—what are we going to do? We’d do that thing—slow down, take a deep breath. I was willing to trot out the board games and read the sentence fluently which was all the therapy was. I was so unimpressed and it was so expensive. Two dollars a minute to teach him ‘turtle talk’ and ‘the slide.’ Brayden always did well during therapy because he wanted to play with toys.

**“We’d do that thing—slow down, take a deep breath.”**

The homework felt stupid and then I felt guilty—like I was being lazy when we didn’t do it, but the therapy didn’t seem like it was doing anything. With three younger siblings, it wasn’t easy to carve out 20 minutes a day to do board games and speech therapy with one child, especially when it wasn’t making a difference. When I finally asked the therapist if she had experience in helping kids this age get rid of their stutter, she said ‘not really, no.’

Brayden is very musical and that’s why I love homeschooling—he can play as much music as he wants. Our little kids notice his stutter and they sometimes bring it up and will laugh about it. They must have mentioned something to Brayden yesterday. He’s usually pretty chill, but when I walked in the room, he asked, ‘can I swear Mom, because I don’t give a *bleep* about my stutter?’ Now everybody knows and nobody cares. He has a sense of humor about it. If he’s really stuck, he’ll just burst out laughing. We try to keep an open dialog and not be hush hush.

This experience showed us that there were times Brayden could be fluent—but that didn’t translate to real life. At least he knows there’s treatment out there when he’s an adult and if he wants to focus on fluency. This experience taught me to trust my gut. I always assumed that when you go to a speech therapist, they know what they’re doing but that is not always the case. There’s nothing out there—it’s just therapy, therapy, therapy to fix. I’ve recently learned there’s a whole community of stutterers that don’t try to make it go away. I think that will be helpful for all of us!”

*Janell, mom to Kendrick, age 4*

“We have no history of stuttering in the family on either side. Our son is now four. He turned three a year ago in December and about four months later we noticed stuttering. My sister is actually a speech therapist assistant and she recommended that we ignore it for now. She said, ‘It can be really common and most likely developmental. Don’t do anything.’ She also informed us that there’s a lot of controversy around speech therapy and there are speech therapists trying to change things and not focus on fixing.

But who listens to their little sister?

After about three months, our son’s stuttering was getting worse and more noticeable. He was struggling so hard at times. My sister had said to give it six months. She had also said ‘if he truly has a stutter, you don’t fix that. He will always have a stutter.’ She was pushing us to not stress, to not do anything but he was having such a hard time, my husband finally looked at me and said, ‘When do we start speech therapy?’

We started Zoom therapy (during the pandemic) every other week and the speech therapist worked on teaching him a technique called robot speech. She was also having him identify smooth or bumpy speech. We would tell him to take a deep breath, think about his words, and talk slow. There was a voice in my head that said, ‘I can’t even do that, why am I expecting my four-year old to do this?’

At first, he thought it was kind of fun. She was someone new to talk to and she played games with him. But after a period, he had started turning his head, exaggerating his face, and really

**“I was frustrated that the speech therapist didn’t share more about the controversies and uncertainty.”**

working to get sounds out. She started doing all these tests on him and I thought he was doing great, but she said ‘he’s not really where I would want him to be for his age. He should be pronouncing certain sounds better; his articulation should be a little better.’ I didn’t want to brush her experience under the rug but I’m around little kids all the time and none of them are pronouncing everything correctly. That was my first red flag about therapy. She wanted to do more testing and felt like he

needed one or two days a week of speech therapy.

In between that appointment and the next test, his stutter was severe. I told him to go slow and say it again. He said, ‘I don’t want to do that.’ He has always been a complacent happy-go-luck guy, so this surprised me. My heart was breaking.

#### **A turning point:**

I texted my sister and she said ‘I think you need to find some support groups’ and that’s how I stumbled on to the *Voice Unearthed* Facebook group. I made a post and before they even gave me any tips they said, ‘read the book.’ I don’t want to get super choked up but your experience really helped us with our outlook of stuttering and our attitude and confidence in helping our son. Reading your book, I felt at such peace with his speech. I didn’t care what he sounded like. I told my husband ‘I know this sounds crazy, but I think I want to pull him out of speech therapy. Just read this book and tell me what you think.’ He messaged me and he said, “absolutely take him out of therapy. I’m so glad you found this book.’

I think you've changed the course of our son's childhood. I thanked the speech therapist for her time but told her I'd rather see him speak than not stutter. When he's old enough and says he wants to go to a speech therapist, that's his choice, his path.

Our son has grown in confidence since we quit therapy. His preschool teacher reported that 'when he's excited, we might hear it a bit, but he's so confident for his age, it doesn't matter.'

I was frustrated that the speech therapist didn't share more about the controversies and uncertainty. All she said was that he just needed more speech therapy. Ever since I read your book, his severe phases don't hurt my heart the way they used to. When it's bad you hear it but it just doesn't carry the emotion. For us to feel less emotion and anxiety, well, hopefully we can pass that on to him."

*Janet, mom to Chloe, age 26*

“It’s been a journey. My daughter was three-years old and in preschool the first time we had an inkling of a speech problem. Her teacher pulled me aside and said, ‘Your daughter is not enunciating words the way a three-year old should. She should be speaking more clearly. I think you need to have her evaluated.’ I didn’t understand what the teacher meant but this lady had been teaching preschool for 40 years, so I did what she said.

The closest speech therapist for kids was 40 miles away. This speech therapist agreed with the first therapist, and we started sending her to speech therapy. She was treated for articulation and saw a number of therapists due to their either leaving or a change in insurance. With a few, she just didn’t click.

The speech therapists wouldn’t let me watch what they were doing in the articulation therapy. They’d come out after and tell me she did fine or she didn’t. She hated it. At home we never had any concern about not being able to understand what she was saying to us. All kids are different, and I figured she would grow into her speech. But I followed the advice of what I was told to do by the professionals.

Fast forward to elementary school, it was clear that she had developed a very bad stuttering problem. Over the years, therapy ranged from breathing to speech techniques and neck massages. I thought the therapy was making her feel worse about herself. I remember her saying, ‘What is so wrong with me that I have to learn to massage my neck before I speak?’

She did get teased in elementary school. In several instances she got more upset at the teachers than the kids. Teachers hardly ever called on her because she couldn’t get her answer out right away or articulate it properly. They treated her like she was stupid. A teacher once cut her off when she was struggling. I emailed the principal and explained that she had a stutter, she’s on an individualized educational plan and this teacher really needed to give kids the opportunity to speak, help them grow and not shut them down. I am a nurse and I’ve never mistreated a patient the way that teacher mistreated my child. I was angry. I got an email the next day from the teacher saying she would allow her extra time to speak.

Going forward I met with every teacher at the beginning of the school year. I would tell them to not cut her off and be patient with her. In school-based speech therapy, they would give her 60 minutes with a group of 40 kids—most who did not stutter. Some had reading comprehension problems and other issues. This was not helpful and we stopped school-based therapy and kept going to one private therapist after another. I was the mom, and this was what we were supposed to do—sit in traffic during rush hour—anything to fix it.

**“I was the mom, and this was what we were supposed to do—sit in traffic during rush hour—anything to fix it.”**

My daughter was doing a lot of tricks to compensate. She started jerking her head and would develop little opening lines for people to avoid saying her name.

**A turning point:**

She went off to college and that's where I discovered that her college had a speech program focused on Avoidance Reduction Therapy (ART) for stuttering and I talked her into checking it out. At first, she was mortified because she didn't want anything to do with speech therapy, but once she got going, it's been fabulous. She has learned how to accept her stutter and embrace it. Now she has a lot of confidence and has been very involved with the National Stuttering Association.

When I watched her struggle, I just wanted her to stop. Why couldn't she just stop? I believed she was not practicing enough and not doing what the therapists told her to do. I saw such a change with the focus on avoidance reduction. She taught me a lesson. It's okay to stutter, to own it, to not be ashamed. Shame on me for being ashamed by it.

The new therapist gave my daughter her life back. It was a miracle and it shouldn't be a miracle—it should just be status quo. My daughter is now very extroverted, and she wasn't when she was younger. Self-acceptance helped her move on with her life.”

*Jody, mom to Tony, age 13*

Tony stuttered right away when he first started talking. My husband worked at the hospital, so he got us on the list to see the speech therapist there. She thought it seemed developmental—nothing to be concerned about. She mentioned the whole thing about thinking faster than he could talk and I was hoping that was the case.

His struggle continued and in grade one, I got in touch with the speech therapist at school. She worked with him a bit and he didn't mind. He got to miss class time which he really didn't mind. At the end of the year, she put in his file that she thought he was doing fine and didn't need any more speech therapy because his stutter was gone. I thought, whose kid is she talking about?

At their school, the speech therapist doesn't see the kids very often. They have a speech therapist assistant who gets about two days of training and away they go. Therapy focused on increasing fluent speech using a modified Lidcombe approach. I had no role in the Lidcombe therapy. This Lidcombe focused on positive reinforcement of smooth speech and acknowledged bumpy speech in a gentle and supportive manner during therapy sessions. By June they reported that he was able to identify smooth vs. bumpy speech, he was able to fix or smooth out the bumpy speech at times and had dropped from 6.6% syllables stuttered to 2% syllables stuttered over the course of his therapy session. I don't know where she got the 6.6% from—he's never only stuttered 6.6%. He'd often stutter more than once in a word. At home his speech was worse.

We then started doing private distance therapy with a speech therapist who had some experience with people who stuttered. She mentioned sending us a booklet to support her approach but that never happened. Every Zoom session she directed us to a free website—it was for aphasia. Why am I paying \$110 an hour for free site on aphasia? We had found her on the licensed web page, so we expected more.

One thing she did was suggested the Institute for Stuttering Treatment and Research (ISTAR). They were not close to us but had a three-week long summer program with parent involvement. Tony was stuttering a lot and it was getting worse. He had gotten to the point where he would just stop trying to say what he wanted to say. During the ISTAR summer program, he learned easy starts and smooth blending. He seemed to do pretty well there, and he met some other kids who stuttered which was probably the best part. He kept up with one boy for a while. After we got back it seemed like it made a huge difference in planned speech but never in spontaneous speech. The person completing his ISTAR report added an extra box and marked his stutter as profound. It was so bad that they had to create a new category for him! I was hopeful that if he was able to keep practicing, he would try to apply those strategies in spontaneous speech. He still asks to practice each morning, but his speech is no better.

We also tried choral reading/recording and he does this for presentations. He didn't want his presentation played for the kids because the kids would think he was faking when he stuttered. Then we were told about a speech easy device. We paid \$4,500 in October and it didn't even have a short-term effect. I don't regret doing it because I would be racked with guilt for not trying. He's still going for sessions for school and practicing ISTAR strategies. I know he doesn't say what he wants to when he's in a group.

He was amazing at ISTAR and during our speech time at home, but there was no carry-over. It wasn't working. I started your book after our first time going to ISTAR and I didn't get very far. I didn't want to quit working on the strategies because I can't imagine how he will move forward in life without some improvement. At the same time, I wanted him to keep talking and to encourage that. It's really hard, as a parent, to let go of the thought that he maybe could be fluent. I see him at the table with family and he doesn't talk. I want to make it easier, but all those other things are not working. He's still receptive to going to therapy so I'm hesitant to stop. I'm still clinging—I can't let it go.”

**“He was amazing at ISTAR and during our speech time at home, but there was no carry-over.”**

*Jonas, age 22*

“My mom wanted me to be fixed—in any way possible. I stuttered so much when I was a young kid, and this became a considerable source of stress for her. The speech therapist would tell her, ‘Your son’s fluency was really good today’ and I would get home and my fluency would be horrendous. It’s weird to have that degree of polarity in the same day. I’d see the frustration in my mom’s face. ‘Come on, try harder.’ The speech therapist would have my parents reinforce what I learned in therapy by giving me a visual cue to use my techniques. I don’t think my parents fully understood just how uncontrollable the stutter was. The speech therapist tried to explain that to them but at the same time the therapy still focused on controlling it.

Classmates didn’t understand and sometimes the techniques, no matter how hard I tried, would simply not work. That was really hard. A lot of the kids were not very nice about it. You could

**“I would like to have shifted to acceptance when I was younger.”**

see them snickering. Every teacher I ever had was very patient because the speech therapist worked so closely with them. All of my teachers were informed of the nature of stuttering and that it would take me awhile to get through presentations. Even with their support, classroom presentations were hands down the most

awkward, really almost unbearable experience.

Up until the end of middle school, stuttering less was always the emphasis. When I got to high school, the emphasis shifted towards accepting. I would like to have shifted to acceptance when I was younger. I think that would have lessened some of the feelings of humiliation and just full-on resistance. So much of the stutter is trying to resist. Acceptance instead of always battling against my stutter could have mitigated my stutter. I would have liked more of an element of how to deal with the negativity in conjunction with lessening my stutter. A lot of this is from hind-sight—from my perspective of being much older.

One final thing that I’d like to add—you hear of all these people who have become famous through the use of their voice—James Earl Jones, John Stossel, etc. I can’t help but feel frustrated by the fact that while they found a way to effectively eradicate their stutter, it painted the message that success is not stuttering at all. We all know that James Earl Jones and John Stossel—if they still stuttered—they probably wouldn’t be in the movie and broadcasting roles.

I just joined the Stuttering Community a few months ago. I definitely like how it makes me feel not so alone—so many people from all walks of life who stutter. A good place—stuttering can be kind of depressing and it helps having a group where you can see thousands and thousands of people like you.”

In high school I did cross country, indoor track, and outdoor track. It definitely enabled me to feel more confident talking one-on-one with people because a lot of people were very friendly, and we all liked running. I had a close group of friends who were not bothered by my speech.

*Julie, (also a speech therapist), mom to Ada, age 4*

**No turning point needed:**

“I graduated in 2015 with my Master’s in speech pathology. In college my professor said, ‘Don’t bring attention to stuttering until elementary age and then we start working with them.’ She also said, “don’t make them aware of it if they’re not aware.” At the same time, she admitted that other people say, ‘yes, make them aware.’ So, which one is it?

We had one course on stuttering in college and then we had to work with one child in the university clinic before we graduated. In college we learned about things like easy onset, where you ease into the word and kind of use your breath to control it. We had to make a chart where you could keep track of disfluencies. You would listen to their speech and put a mark wherever the disfluency was which was really hard—and the client knows what you’re doing. Then what do you do with that number? That was supposed to be the starting point for therapy. Okay, I have this number for you and now you need to work on it. I really don’t get it.

That was all the experience I had before going out into the schools and doing it myself. I had a few fluency clients on my caseload, and I felt very ill equipped to work with them. I was just asking questions like shooting in the dark. I felt like walking on eggshells a little bit because I wasn’t settled on exactly how to go about it

**I had a few fluency clients on my caseload and I felt very ill equipped to work with them. I was just asking questions like shooting in the dark.**

Two years later, my husband and I had our first little boy. I continued working part-time in the schools. Around the time our son was about two and a half, he started having a stutter. I knew that can be typical for that age and that about 80% grow out of it. But that didn’t really matter to me, I was still anxious for my child. Six months went by, and we

were even more concerned. Then a year went by, and I was like, okay, I need to talk to somebody. I don’t know what I’m doing as I’m not as skilled in the area of fluency as I’d like to be like, I don’t want to mess him up or make him stumble over his speech more.

I reached out to a colleague, well-known in the field, and he said, “he still has some time but here are some indirect ways to help. You guys need to slow down and just let him talk at the dinner table—things like that. Give it some time. Over the next half year our son would go through periods of smooth speech and then it would be really bumpy and hard for him to communicate with us. I didn’t know whether to say anything to him at this point. I think I said, ‘Yes, this is called stuttering and it’s okay. Some people have bumpy speech.’ I was trying to let him know it's okay.

After about another six months his disfluency was really high. I was more anxious than he was—he didn’t really notice it. One day I had to leave the room because it made me so tense. At the same time, I was evaluating preschoolers. So, I was in the middle of researching myself and trying to figure out what exactly I’m going to say to parents who have this concern. Here I was in the same boat.

I would love him to recover but I feel like it's challenging to treat correctly, if there's a correct way. I think the goal should be communicating and talking and getting your point across—and not being fearful of that and not overthinking what you're saying. I don't think it's bad to tell the kid, 'You're learning how to talk and you're learning how to run and different things like that. But the most important thing is, I want to hear what you have to say.'

I would tell a parent to give them some space and time to finish what they're needing to say even if it's awkward for you or the child. Then maybe you can reiterate what they said and make sure that it's what they were trying to communicate. Just allow them to feel like what they're having to say is important. And yeah, just letting go a little bit, I guess.

Our son still has some disfluencies and pauses but it doesn't bother me as much after talking to my more-experienced colleagues. So that's where we're at right now. It's different when you're a speech therapist and the mom of a kid who stutters. It's a different perspective. I think it's kind of a little bit of a blessing in disguise. Now I'm on the other side of it, and I can understand a little bit more of the worry that a parent goes through.”

*Karen, mom to Betsy, age 11 (both stutter)*

“I’m an adult who stutters and when my daughter began to stutter, that sent me on a complete tailspin. My own baggage surfaced as I watched her struggle and I wanted to give her the best shot. I didn’t want it to be like it was for me, so we jumped into speech therapy right away.

We did that for a while, and she was fluent in the clinic setting but she became very quiet outside of that setting. It would take her five minutes to get three words out. That went on for a few years.

**A turning point:**

Then I came across your group. I was posting every week. That group was my lifeline for a couple of years. I finally found a new therapist trained in parent child interaction therapy and she started working on self-acceptance. I love this woman. She has a good handle on the emotional side of stuttering and anxiety and all the other stuff. It’s been three years with no type of direct therapy.

I’m still trying to raise her self-confidence. She loves dancing and singing so I focus on that. There’s always the hope that it’s going to go away but I finally gave that up. I feel like she’ll end up something like me, maybe with a bit more struggle than I have. She talks non-stop and it’s music to my ears. She’s got a few really great friends that she has lots of laughs with.

**“The parental support element is the biggest part. Watching your kid struggle is so hard.”**

In a book the speech therapist gave me in 1985, there was a picture of an iceberg. \* That iceberg definitely became a thing in my life but nobody ever talked to me about it. Anxiety, fear, avoidance, well, that sucks! The parental support element is the biggest part. Watching your kid struggle is so hard. You feel like you caused it. I understand looking for an answer—it’s the knee-jerk

reaction everyone has. Dealing with your own issues and developing acceptance around the stutter is huge.

You have to go through acceptance and loving your child for who they are and accepting them whole-heartedly. There’s a grieving process—letting go of who you thought this child was going to be. Now I’m very happy with my kids but there were days, even years, when I was a mess. Then I got sick of it. I couldn’t handle watching her struggle. I posted in the Voice Unearthed Facebook group and found a therapist to help me wrap my head around it all. I was really unhappy with how I was handling it. Somewhere along the way I let it go. It was a huge load off. Now I can talk about it, advocate for my kids, and teach them to advocate for themselves.

Anxious parents watching every word that comes out of their kid’s mouth—not good. Support your child, concentrate on things that make them happy. Teach them to advocate for themselves. It’s okay to talk different. It’s the same way you would treat any other disability. You would not tell a kid who can’t hear that they should hear. You can’t make it go away. It’s either there or it’s

not. But you can do things to minimize the exacerbation of the impact the challenge has on these kids' lives.

A parent can contribute a lot towards the child's inner voice. Maybe people have to go through the fix it journey—first instinct. It's a learning curve—this is going to fix it, no it's not, let's try it again. You have to take a few hits maybe? But can we shorten that journey—of chasing the fix. Pull back, have some fun, enjoy life.”

\*<https://www.stutteringhelp.org/blog/sheehan-stuttering-analogy>

*Kaye, mom to Isaac, age 10*

**No turning point needed:**

“Isaac was three when he was first diagnosed as stuttering. The Stuttering Foundation of America referred us to a specialist in our area who practices avoidance reduction therapy. That speech therapist said “I don’t want to treat your son and here’s why. Intervening too early is not actually that helpful.” She sent us to a colleague to help us learn how to best support free-flowing communication at home. She encouraged us to not send our kid a message of shame or the idea that this is something that needs to get fixed.

Once our son started school, we were encouraged to get him an individualized educational plan and start school-based speech therapy. While our school district has an army of speech therapists, not a single one had any training in fluency, yet the district insisted we needed to fix his fluency.

This was in complete opposition to the guidance we were getting from our private speech therapist who has extensive training in fluency. They wanted to teach him fluency shaping techniques and how to switch his words. All I wanted was a speech therapist who knew enough to know what they don’t know instead of wading in with ‘let’s throw a bunch a stuff at this kid and see what sticks.’ Our private speech therapist told them that if the school-based speech therapists moved ahead with what they were proposing they would be actively causing this child harm. We denied speech services in the school setting because in our opinion, they were not willing to not do harm.

**“All I wanted was an speech therapist who knew enough to know what they don’t know instead of wading in with ‘let’s throw a bunch a stuff at this kid and see what sticks.’”**

It's still a nightmare out there. I've often wonder if the Stuttering Foundation of America had directed us to another fluency expert with a different mindset, where would we have ended up? Our private speech therapist's therapy has been very successful in eradicating secondary behaviors. He's now willing to tell people he stutters, and he stutters openly. He realized that all the energy he put into trying to hide the stutter is not needed. I feel very blessed to have started my stuttering therapy in such a healthy place.”

*Kim, age 52*

“We lived near the school where my mom taught. My first memory was my dad taking me to the school to meet my mom and the school therapist when I was about four. I got the feeling then that stuttering was bad because oh my goodness, why am I in this tiny space with this gal who is just watching me talking? Why is she doing that?”

I had school speech therapy until about fifth grade. My parents listened to me saying ‘done.’ I didn’t want to be pulled out of the room to go to therapy anymore. Kids knew I stuttered and they stuck up for me. I think it helped that my mom taught at the school. The same core kids came to high school so that helped too. I didn’t let it stop me socially. So many accepted me as I was. Many kids who stuttered didn’t have that.

My parents never made it a big deal. My dad was more confused because I would talk fine some of the time and sometimes, I couldn’t say a word, He’d ask me what was going on and I’d tell him I just didn’t know. My mom, being a teacher, she just knew it was ok, it was just me. Back then nobody knew that much.

So, in my senior year, my parents heard of a camp for kids who stutter and asked if I wanted to go. I said, ‘yea sure, why not.’ My having the say of going was good. That was the first time that I recall going outside the clinic setting. This was huge, real-life stuff. I couldn’t stay in the clinic making words and sounds. I had to go outside the clinic setting to stutter, to talk. I had to start living my life, but my fear was huge. These fears took many years to get over, so I want to say don’t let your fears take your years away—don’t let them do that! It’s sad. Knowing the role fear plays in a kid’s life is huge.

**Knowing the role fear plays in a kid’s life is huge.**

When I turned 28, I heard about a program where they have you go out and talk to strangers. I thought, ‘oh I could never do that. No way, I’m not going. Stop telling me about it! There’s no way. Absolutely no no no!’ Twenty-nine came and I told myself, ‘You’re going, you’re gonna go over there and get this lassoed’ and by God, I called and signed up. Now it’s coming up and I’m too scared again, too scared. So, thirty came and I said to myself, ‘you’re 30, let’s do one more speech therapy because it’s time.’ So, I called them again and said, ‘okay, this time I’m really coming.’ They changed my life.

There is no way back then I would have said ‘please call me Dori! I would love to talk to you! You’re going to record it? Oh sure, go ahead.’ No way! I wish more stutters knew that most people don’t care. They have their own stuff to deal with.

They said, ‘you stutter, you’re never going to be cured.’ Ok, check, got it. Then they proceeded to peel back those years of gross, hateful, shameful stuff. It was huge. They taught me techniques and helped me to know that when they don’t work, I’m still okay. My God—I was like ding ding ding and the light came on!”

*Kyle, age 33 (son of Constance)*

“I saw a speech therapist in grade school, but I don’t think it had an impact on me nor do I think it was helpful. At that time, I could hide my stutter—I forget how I did that. My family was accepting, and it wasn’t that big of an issue to them because I didn’t voice my hardships and I was so good at hiding it. I think having conversations with my parents would have been helpful when I was young.

When I was in grade school and my mom wanted to find access to a speech therapist, she went to the doctor. The doctor referred her to a speech therapist and it’s all up to whoever that therapist is and what they learned in school. The speech therapy I had was big on easy onset and didn’t get into the mental frame of mind and the strength of accepting your speech. I know the sooner I embrace it and avoid hiding and masking, the better I’ll be. I’ll become more accepting of who I am, for better or for worse.

**A turning point:**

Group therapy inspired by the idea of avoidance reduction was very transformational. It focused on mental accepting and advertising, and it has paid its dividends. The public advertising has helped me become more accepting, boosted my confidence, and I believe helps increase awareness out in the world. These days I’m constantly presenting and giving direction to people in my job so I can’t hide from it.

**“– not stuttering isn’t the goal. Accepting who you are and what you have is the goal.”**

Avoidance reduction therapy is an interesting concept.—not stuttering isn’t the goal. Accepting who you are and what you have is the goal. The end state is not to not stutter. The hardest part of any disorder is acceptance. Once you’re past the acceptance phase, you start to gain momentum. Although I still try to hide it to this day, I don’t hide it near as much and that’s been kind of transformational.”

*Lane, age 39*

“I started to stutter between three and five years of age—the age when language starts to develop. I don’t remember a time when I didn’t stutter. My pediatrician told my parents the age-old wisdom, ‘he’s gonna grow out of it.’ He didn’t tell us that if I hadn’t grown out of it within two or three years, I was most likely to be one of the 20% who would not grow out of it.

I went well into my teens thinking I was either going to stop stuttering by working hard or I was going to grow out of it. Whatever it was, there was no doubt that I was supposed to stop stuttering. That was as clear as the direction you put your pants on in the morning. But it wasn’t working and I didn’t know what to ask for.

I was home schooled until sixth grade which meant I didn’t have the more typical experience as a school-age kid. I was in Cub Scouts and in religious school and my parents worked hard to make sure there was a social network. In sixth grade I was in a classroom setting for the first time. It was English class, and we were going around the room reading from our literature books. This is normal for everyone else, but it’s the first time I’ve ever experienced this. I was freaking out. I can see it to this day. It gets to my turn, and I hadn’t yet learned any of the tricks to avoid these situations. Nothing comes out of my mouth—a total silent struggle—complete shutdown for what felt like an hour. It was maybe a minute, maybe less, and then the teacher moves on.

This nice kid comes up to me afterwards and offers to help me learn how to read because he thinks I don’t know how, which was a reasonable conclusion because when it was my turn, I couldn’t do it. He was being kind and I was heartbroken with no ability to process what had happened and why it was happening, I didn’t know how to talk about it, so I just didn’t.

I was referred to the public-school speech therapy and given a speech book for practicing my sounds. We would practice my b b b b and then we get to two-syllable sounds. It turns out I was really good at it but of course it didn’t help me with my stuttering.

My efforts to not struggle were spiraling into a museum of tricks and avoidance behaviors. For instance, I had this thing I did with my left knee that helped me get out of blocks. I was flailing through while being told that everything was fine and I’d grow out of it.

In middle and high school, I went to speech therapy in public school for a half hour each week. The speech therapists were lovely and well-meaning, but they didn’t know how to help me. My family wasn’t engaged and there was no broader conversation or discussion. It was all about how do we get the stuttering to stop? I learned how to do prolongations and bouncing, and I could do all of these things pretty well in the therapy room.

When I started college, I was a 19-year-old young man white knuckling it all the way. No one was gonna tell me anything. I was angry and hellbent to prove to the world that I didn’t need therapy. Are you kidding me? I’m fine! By the end of the first semester, I crashed pretty hard.

**A turning point:**

**...there was no doubt that I was supposed to stop stuttering. That was as clear as the direction you put your pants on in the morning. But it wasn’t working and I didn’t know what to ask for.**

My speech therapist in high school had told me there was a great speech clinic at my college and maybe I should check it out. I hesitated, but when I finally connected with the speech pathology department, I connected with an awesome and amazing therapist who worked with me to “de-awfulize stuttering.” He was also the first person I ever met who stuttered.

During the seven years I attended under-grad and graduate school at this college, the therapist worked with me one-on-one and started an adult stuttering group focused on helping us shift from defining success as fluency to not valuing fluency at all. We now had the language to express what we really wanted and needed—to work on effective communication that would be joyful and lead to confidence and success. There was something incredibly magical about being together with all of us working in the same direction, struggling with the same things, and having the same goals.

After college, I moved to Baltimore and connected with the National Stuttering Association (NSA) chapter. The expectation in the working world I was in now was so much higher than graduate school. This is when I was introduced to therapy focused on avoidance reduction. At first, I thought it was crazy stuff because they wanted me to do the most ugly, uncontrolled stuttering I’d ever done in front of people. The only reason I came back after the first session was that this therapist had been recommended by people I highly respected including my college therapist.

In group therapy, I watched these people stutter just like I wanted to stutter. They were communicating so well. They were smiling and not struggling even though they still stuttered. They seemed to be in a better place than I was. I was getting there.

I continued to struggle as I went through life transitions. I moved across the country another three times since my days in Baltimore and I changed jobs several times. It would be nice to have stuttering just disappear and never have to deal with the challenging situation when a co-worker is hearing my struggle in my speech. I see the confusion and feel the need to explain a bit so they understand. I don’t know that I’ll ever be all the way there and fully comfortable as a person who stutters.

At work I know I’m a good communicator and yes, I stutter. I have times where I struggle a lot more because that’s how things work, but I don’t think I can lose the belief I hold now that it’s not the stuttering that hurts and it’s not the fluency that helps. Communication is about so much more. We can have joyful communication while being people who stutter, and we can say what we want to say when we want to say it and express ourselves with confidence. Knowing that and living that is a total gamechanger.

One of the things we sometimes struggle with in the speech and language community is early onset when kids are three. We still try to fix the stuttering we really do a disservice to these kids and their families when we have a narrative that first says we need to fix it, and then, well gee, it sounds like you’re gonna stutter all your life so let’s talk about acceptance instead. Even when we’re three and starting to stutter, working on not avoiding rather than fixing is still more productive. The message does not change, and if the stuttering goes away, cool and if it doesn’t, ok.

These days we talk about client driven therapy and working on what the client wants. In hindsight, I can say I understand I wanted to work on effective communication that would be

joyful and lead to confidence and success. That's what I really meant when I said, 'I want to stop stuttering' but I didn't have the language to say what I really needed and neither did the people who were trying to help me."

*Laura, mom Jacob, age 22*

“Our son started speech therapy at 11 or 12 when he asked for help. His whole personality was changing. We asked to be put on a National Health Services waiting list and we did not have a choice of therapist. Who he got I could not fault—she was amazing.

She did very little technique and more about working on him as a whole being rather than ‘this bit isn’t right.’ By this stage he had secondaries, tics, severe blockages, his entire tongue would come out. He got more self-conscious about that than the stammer because he felt he looked mentally and physically disabled. In his eyes, he didn’t want to look like that, so he just didn’t talk.

He was also getting into fights and trouble. This kid was going to end up self-destructing if we didn’t get help. The therapist talked to us separately. She asked about our pace of life, and I told her that he had a very busy schedule and I’m neurotic about time. She told me to take off my watch—and I haven’t worn a watch since. She could have said, “chop of your right arm” and I’d say ‘that’s fine, I’ll learn to write with my left!’ Do you know what I mean?

We cut out extracurricular activities that he wasn’t 100% behind. We ditched tennis but kept rugby. She met with him once a week for five years. It was a total fluke that we got someone who wasn’t focused on tools. He had a great rapport with her and looked forward to going each week.

**It wasn’t his speech I wanted fixed, it was his heart.**

They talked about what he liked and didn’t like, what he was struggling with in school, who he was struggling with, his insecurities, positivity circles, what was good today, gratitude, and lots of positivity molding. She made him talk a lot in front of a mirror with her. When he started to stammer or had a tic, she would go, “now you see where your shoulders are?” When he could feel himself, he learned it was okay to stop talking for a minute, relax, and then start again. It was all about being grateful and look for the good in things. We hadn’t even known this type of support existed.

Quite quickly his energy changed. He became less aggressive, less angry. Those were the things that were getting in the way for him at that point. The secondary tics lessened, his confidence started to grow, and he started to talk more. It was a hard, painful process. There was nothing I could do to fix it, it had to come from him. It wasn’t his speech I wanted fixed; it was his heart. He wasn’t a bad kid. He wasn’t less than anyone else. He focused on what he was fantastic at and that was rugby. For another child it might be drama or music. It’s just finding the thing for your child.

Our son will be a qualified teacher by the end of June. His primary teachers were so supportive and he wants to pay it forward. He’s been doing lots of Zoom interviews. He always starts, ‘hi, I’m Jacob, I have a stammer, no worries,’ but he finds listening back to the video very challenging sometimes. He’s building resilience. He’ll be a great teacher.”

*Linda and John (parents to 41-year-old Courtney) and Courtney joined in too.*

**Mom:** “I stuttered, and I guess I was one of the 20% who just stopped. Our daughter’s older sister also had some disfluencies and she stopped so I thought, okay, that’s what happens. I didn’t think anything of it at first and the pediatrician suggested we wait, but it got to the point where I had seen her suffer enough and we started taking her to therapy. As a parent you think there must be something that can be done. I needed to actively do something to help them.”

**Dad:** “Our initial goal was to help make it go away.”

**Mom:** “Eighteen years later, in 2004, she was in college, and we went to our first National Stuttering Association conference. Our daughter was a new college graduate. I remember looking through the program thinking ‘God forbid we miss THE talk that was going to cure her.’ I can picture this—it was so heartbreaking. We were in the hotel room. She opened up for the first time and told us how horrible it made her feel when we took her to therapy knowing that we wanted to fix her, and it wasn’t working. It was as if she was disappointing us.”

**Courtney:** “We were all sold the wrong story. I WANTED to be fixed and the therapist said you SHOULD be fixed and we COULD be fixed.”

**Dad:** “It was not geographically convenient to us at all, but someone must have told us that the therapist we went to was the best—that would have been our MO.”

**Mom:** “Here we are—the distraught, unknowing parents. We didn’t know what to do or how the hell to help them. This therapist told us she had grown up stuttering and had developed a machine that she said worked for her. She was fluent—so I thought, “OKAY! Here we go.’ The machine measured the movement of the diaphragm. We bought one of the first Apple computers in order to use this machine. Courtney practiced and practiced. Sadly, when you’re parenting, you don’t know what you don’t know. You throw a dart in the dark and hope the dot you’re picking is the one most appropriate for the issue. You have no context to provide some degree of assessment.”

**“Sadly when you’re parenting, you don’t know what you don’t know.”**

**Dad:** “Could I have done more—or something different?”

**Mom:** “When you stop therapy, you feel like you have now failed your child.”

**Courtney:** “It’s your fault Mom, you talk too fast.”

**Mom:** “We were told you talk too fast.” (laughter)

**A turning point:**

**Dad:** “The iceberg analogy\* was like a light bulb going on for me. The disfluencies were the tip of the iceberg and when our daughter engaged in activities focused on desensitization, the iceberg got smaller. That’s what the therapy she received as an adult, therapy focused on avoidance reduction, did for her. For sure—the focus on fluency did more harm than good.”

**Mom:** “You’re just setting the child up for emotional stress, failure, depression. We need to help our kids to have the most joy out of their lives. In America, everything needs to be cured. How

many years do they dupe their patients before they say, 'this is not working.' Most clients just peter out or blame themselves."

<https://www.stutteringhelp.org/blog/sheehan-stuttering-analogy>

*Lorna, mom to Edward, age 11 and Frank, age 21*

"Edward's current speech therapist has been there more as an advocate, asking us what would help him transition to high school, what to tell teachers and others. But just a couple of days ago

she tried some therapy with him, deciding to get him comfortable saying his name. He came home and said, 'I don't like this therapy, she's making me talk!' He's had a bad week—kids being mean. That was just the final straw. It's hard for him to tell us things, especially things he's not enjoyed like kids being mean to him. He stutters more then.

During previous therapy we did a video session at home to be shown at therapy. It was supposed to be a five-minute video, but it was more like 20 minutes because I had to get it right and tidy the room, etc. She would comment on how we did—I felt judged. We do play with our children and we take them places—I felt like I was being judged as a bad parent.

We have three children with a large age gap. Our 11-year-old is the youngest. The speech therapist said, 'there are lots of adults in the house and it's hard for your son to keep up with the chatter.' It felt like we were being told off for being who we were. Again, I felt judged. During the making of the videos, his speech was fluent and relaxed, and she felt it was going well. I didn't let on how stressful it was. She was quite a stern lady and I'll admit, I was a bit afraid of her.

We encouraged rugby so he'll make more friends. He also joined a youth group and he's loving that—meeting new people, doing cooking, art classes, other stuff online and now they're playing games in a park. It's a local youth group with youth leaders. When he first joined the group, they asked them questions and they would shout out the answers. This was difficult for him, and I sent them a message about his stammer. They asked for information. Now they type the answers in a group chat instead of shouting them out. He's talking more and comes back from the group meetings really energized. We're finding things like that are really helpful. They need social connection and confidence. Sometimes this gets lost in the quest for therapeutic help. When he has to concentrate on his speech, it makes his speech worse.

Our 21-year-old son was five when he was referred to speech therapy and most of the work was on fluency—a sliding technique. He had a lot of facial tension. Therapy was very much focused on helping him talk more fluently. He didn't really like speech therapy. We didn't do much practicing at home. She advised us to reinforce strategies at home, to give him time, and make good eye contact. Speech therapy stopped when he was 11. He didn't want it anymore. He probably winged it and made himself sound quite fluent in the last session. He quietly got on with it and found his own strategies. He gained more confidence as he got older.

I wish I had gotten more information on how to support a child. We were never told that a speech therapist may not be trained in stammering. We assumed that that they would fix it but our therapist admitted she didn't know much about stammering but she has been more of an advocate—not there to help with fluency. I appreciate that.”

*Louise, age 67*

“My upbringing was quite bad, and I don't share with many people. At age three or four, I kept asking my mother, 'when's my dad coming home?' She'd say, 'he'll only come home after you talk properly.' When I went to primary school, if you stuttered, they just slapped you on the head. Today they would end up in jail!

When I was about nine, I went to speech therapy every week with my mother on the city bus. We would ride past a place where girls had babies if they were young. Every time we drove by, she'd say, 'look, if you don't talk properly at speech therapy I will drop you off there and as far as I'm concerned, you can stay there and die.' She would scream at me all the way up and all the way back. My mom was a widow and there was a lack of education.

In those days in therapy all you really did was blow ping-pong balls around. I understand now it was the breathing they were focusing on. You used a straw to blow the ping pong ball across the table. That's really all it involved.

I had no therapy after age nine. Kids walked around and pointed their finger at me and called me 'the stammer girl.' My teen years were horrendous. When I was 16, mom had a stroke and my oldest siblings said 'You'll have to look after her. You can't talk properly and you're really ugly and who will want you anyway?' From the time I was 16 until she passed when I was 28, that's what I did.

My sister's brother-in-law used to visit, and I became interested in him, but my sister said I was wasting my time because he wouldn't want me either. I wrote him a letter and he came over again and then we carried on and got married and had two boys against all odds.

People ask if I didn't have a stammer would I be happier? My stammer has helped me to meet so many people through Facebook pages. Facebook pages and groups changed my life! If I didn't have a stammer, I'd just be a boring old lady. Having a career in the field of early childhood was also a blessing. Now at 67 I know when people see my coming, they won't say, 'Here comes the old lady with a stammer.' Instead, they will say, 'I wonder what fun she is planning now?'

**"Now at 67 I know when people see my coming, they won't say, "Here comes the old lady with a stammer." Instead they will say, "I wonder what fun she is planning now?"**

Encourage your kids, help them build their confidence. Stammering does knock your self-esteem. You can follow your dreams, do jobs, and have relationships. I just want all of these people to know this at an earlier age than I did!"

*Maeve and Rory, parents to Connor, age 5 (both Rory and Connor stutter)*

**Mum:** "When our son was just over a year old, we consulted a speech therapist having more to do with language delay. They diagnosed glue ear and once that was resolved, the language delay resolved. He started coming out with loads of words in a short space of time. We were just about to be discharged from speech therapy when we noticed him beginning to stammer. He was just over two years old.

I have to admit, at first, I felt sadness. I didn't want him to have struggles or have experiences in life where people were not kind to him or not understanding. I didn't want him to feel the frustration of that. At the same time, my husband has achieved a lot and he stammers. I would not choose for our son to have a lifelong stammer, but I know it's not the end of the world. His father has a successful career. He leads a team. He has to talk in team meetings and he appears in court as a witness. He doesn't avoid things at all. Dad is a great role model for how everything can be fine.

Our son stammered pretty consistently for about a year and a half without a break. We had a few speech therapists and realized that general speech language services can be hit and miss when it comes to treating stammering. Our therapists were all lovely, but we got the feeling that they didn't have a lot of experience with stammering. They gave us advice about not interrupting, giving him plenty of time, maintaining eye contact, and recommended taking a 'watch and wait' approach as he was so young.

We had read that there's a window of opportunity for intervening when children are young. I really wanted to take advantage of that window. My husband had learned about The Michael

**“We noticed right away that there was a different kind of level of understanding and level of intervention with this therapy.”**

Palin Centre for Stammering (MPC) in London. They did parent-child interaction therapy (PCIT) and we went ahead with an assessment. Other therapists had given us general advice, but The Michael Palin Centre was very specific and engaged the entire family. We noticed right away that there was a different kind of level of understanding and level of intervention.”

**Dad:** “We were in a unique position really because my wife is a psychiatrist and I've lived with a stammer all my life so there was a lot of lived experience. I think it really helped us to help our son and to understand an approach that didn't focus directly on curing his disfluencies.”

**Mum:** PCIT therapy involved videoing some of our interactions, reflecting on what we saw, and identifying which aspects of communication we could work on as a family. We became more aware of what we were doing that was helpful or not helpful and tweaked things accordingly. For instance, we became better at not interrupting and giving him more opportunity to talk. We played a microphone game where you had to be holding the microphone in order to be in the conversation.

Another example would be a marble run game he loved where you built tunnels for the marbles to go through. Normally we would have provided more direction like, 'that's not gonna work,' or 'let me fix it for you' and 'let me build it the right way.' We realized that it was not about whether the marble run worked, it was about whether he was enjoying the interaction and felt relaxed.

We did special time at home which was five minutes of protected time with him. We would let him choose and take the lead and be the king of special time. Those are some of the things that we worked on.

The PCIT therapist helped us to interact with him about his stammer in an open way, allowing him to express whatever feelings he may be having. What emerged was that he wasn't really aware of his stammer. He wasn't anxious by it or upset. He never developed any tension around talking. He never reached that level of disfluency."

**Dad:** "My stammer kind of made me what I what I am. I did want to help him as much as we could, but we didn't want to make it into some kind of big mission and focus. I even had some ambivalence about should we be treating this at all? I felt like I am the person I am partly because I have a stammer. I don't know what I would be like if I didn't have a stammer. We didn't want to give him the impression that if you have this thing, it's terrible and a big problem—a flaw. At one level we're older and a bit wiser, but at another one level, it is quite hard when you're listening to conversations around stammering and the emphasis often is on, 'this needs to be cured.' It's an aspect of the person and it's really about making it easier to communicate.

We just wanted to help him to be able to talk in a way that was not too pressurized. Working with the PCIT therapist helped us to become more organized, structured and disciplined in our approach. I don't view our son as being cured but he's not in any way anxious about it. He may always have occasions where he's a bit more disfluent but he's not disfluent in the way that he was a year or two ago."

**Mum:** He really doesn't stammer now. He started school earlier this month and I wondered how that would go. It's the first time he's been in a group setting this large. There was one day coming home from school in the car I noticed for the first time in ages he was repeating a sound at the start of a word. I said to him, 'oh, was that tricky? Did that word get a bit stuck?' And he just said, 'yeah, that happens to me sometimes.' And that was it. Very matter of fact. If he's out and about, he's the guy who will begin talking to people. He doesn't hold back. He has this gregarious nature and is very chatty."

*Marika, mom to Villiam, age 15*

“Lidcombe was the only thing we could find. The speech therapist wasn’t a specialist, but she was a speech therapist—it was a program she was aware of. I don’t think stammering was part of her specialist training. I do not know if she was formally trained in Lidcombe. Our son was really too old for Lidcombe. She didn’t know what else to do—so shove Lidcombe at him and see how it comes out.

We did Lidcombe for about six months. We coded on a scale from 1 to 10 where we thought his speech had been on that day. We looked through picture books and used the word “bumps” to describe his speech. That’s what got to him, reading the words out from a picture book. He is really intelligent, so he’d say the word without a bump and then I’d go, ‘yay, that was really good, let’s try that again.’ He’d yell, ‘I can read! Why am I doing this, I can read!’ I was just doing what I was told. He was frustrated—he thought it was an insult to his intelligence. And then I’ve got my daughter in the other room going ‘I want special time! Why can’t I have special time?’

We paid an arm and a leg—60 pounds a session—and the speech therapist was printing off sheets she found for free on the Internet. Thank God my mum gave me a big envelope full of cash to help pay for it.

Then we went with the National Health Service and that speech therapist was rubbish at talking to a nine-year old lad who really didn’t want to be there anyway. She tried to give him different tactics on how to start a sentence, like if you feel yourself going to bump in a letter, think about the word you want to say, stop, take a breath, do a tap, and then slide in. Jesus, he’s a nine-year old kid, he’s not going to do that, he’s just going to say it!

**“Jesus, he’s a nine-year old kid, he’s not going to do that, he’s just going to say it!”**

One technique he used was tapping. His speaking was very robotic, stilted. Then we kind of just stopped because they had given him the tools ‘so off you go.’ He’d have good days and bad days in his speech. We’d go back for regular updates, but nothing had changed. It didn’t help, it didn’t do anything. Yes, I was using the verbal contingencies. I can’t believe that we did that. It was upsetting him but if this was going to fix it then ‘suck it up, get on with it.’ What are we going to do? They’re the professionals, they know what they’re doing.

It was only when I read your book and gained more confidence in myself and my son that I asked, ‘why are we doing this? What benefit are we getting from it?’ The light bulb went on and we moved on.

He was really lucky at school. There were only 180 kids in the whole school, so his friends were the same ones he had joined with when he was four. The kids just got it. The only time he did have a couple of kids say stuff was when new kids joined the class when he was seven or eight. ‘Why do you talk that way?’ ‘Because I have a stammer.’ That was it. After that he actually typed out ‘things to help me when I speak’ and the teacher did a carpet talk about things to do and things not to do.

One time I made an appointment to see a new teacher—just to let them know he has a stammer. The teacher said, ‘I know. He put his hand up and he couldn’t get it out and I finished the word for him. He promptly told me, ‘Don’t ever finish my words for me again.’ She was a new teacher to the school and she and I got along well. She was blown away by his confidence. He didn’t come home and tell me this had happened. I had no idea that had happened until the teacher told me. You hope they were not rude, but on the other hand I thought, ‘go son!!’ She was the SENCO and turned out to be a good partner.

Today, instead of focusing on his speech, he focuses on video games and football. He has thrived and flourished, and nothing has come up about his speech at all.”

*Martha, age 52*

“Your first book really moved me because it said things that I always thought, and I never heard anyone else say. I went through therapy as a child and a lot of what you said in the book resonated with me.

I began stuttering around age four. The local hospital offered speech therapy at no cost. I went there for a long time—for more than 10 years. I don’t have very good memories of it. It was a lot of working on techniques and doing drills. They would have me talk using the various techniques. I had to buy a stopwatch and they timed me speaking 30 words a minute. They were trying to get me to speak more slowly using techniques. At that time, they would have me do voluntary repetitions and stuff like that.

Towards the end of the session my therapist would take me around the hospital for what was called “transfer” where I would talk to people using the techniques I learned in those drills. It was okay, but I didn’t really enjoy that much either. I was just a little kid, and everyone was very nice but I found it all kind of humiliating. That was supposed to be a fun part, but I didn’t find it fun.

There was some urgency about it as I got older. There came a point where everyone was losing patience with me. I have this memory when my therapist had these kids’ books in her office, and she would have me read out of the books and I guess I had a bad attitude. I said, ‘no, I don’t like those books, I’m sick of them, I don’t want to read them anymore.’ She got really mad and said, ‘just read.’ Looking back on it, I can see that I had been going there a long time and I wasn’t very cooperative all the time. I think they believed that I just wasn’t doing enough.

I hope things are different now when it comes to kids because people have realized they need to address the emotional aspects of it and it’s not just about the physical dimension. You can’t train a child the way you would if they were learning dancing or something. It’s emotional—there’s more understanding of that now.

When I look back on it, I think I did feel like my mother didn’t love me as much because of my stutter. She used to drive me to speech therapy sometimes two or three times a week. We drove there in silence.

**“I did feel like my mother didn’t love me as much because of my stutter.”**

I remember there was a time in junior high when I had been going to therapy a long time and they told my mother I wasn’t working hard enough, and I should come back when I’m ready. That generation—you just listened to what the experts told you. I’d like to think

they would have been receptive to guidance. I wish I had said, ‘if me learning these techniques is so important, I’ll learn them if we can talk to each other about it.’ It just wasn’t like that.

Other than taking me to therapy and back, I don’t think my mother believed there was anything she needed to do. Neither of my parents were very verbose people. There was not a lot of conversation or talking in my household. When I was very young, I recall trying to talk to my mother about my stutter. Little kids don’t always have the words—they don’t know how to talk

about how they feel, think, what the world means and all of that. When I tried to talk to her, all she said was ‘the speech therapist says you need to work harder, and everyone wants to help you.’

I didn’t do any extra talking in school other than what I had to do. I was very shy, and nobody encouraged me. I remember in junior high there was a teacher going around the class asking us about ourselves. It was like I didn’t care anymore, and I wasn’t even nervous and I just said, ‘well I stutter.’ I almost get the sense that I could have gone a different way at that point in my childhood—towards not caring. I look back and I regret that I worried about it so much and I cared about it and thought I was so terrible and why would anyone want to hear my awful stuttering. But there was a part of me—it was like there were two different voices in my head and the one that won out was the one that said ‘shut-up.’

I would even go on the intensive courses and by the end I would not stutter. That would last about five days. After the course, people would say they noticed it was better and then they’d say they noticed it wasn’t better anymore. What stands out in my mind are people’s reactions.

As an adult I’m more accepting of myself. I’ve tried all kinds of therapy over the years. I guess through all of it, the biggest thing you learn is that you’re not alone and there are other people who know what you’re going through. You don’t have to go through it alone.

I notice it the most when I meet a new person or when I get a new job. I stuttered in my job interview so they know I stuttered. I can’t hide it, I’m not covert. I don’t even try to be because if I did, I wouldn’t be able to say what I want to say—I would just hide my stutter.

A parent needs to know that fluency isn’t the most important thing. There are so many other things that are more important when it comes to your child’s speech and their emotional well-being and self-esteem. The thing that will make the biggest difference in your child’s speech is helping them to have communicative relationships with other people. When I say ‘communicative relationships’ I don’t just mean talking. People communicate in other ways too. When a child has close relationships with other people that are deep and rich and meaningful, that will do more for them than any speech therapy.”

*Mary, mom to Seamus, age 17*

“Seamus got up one day and he couldn't speak. I did a double take. He'd been absolutely fine the night before. I probably said, ‘let's go and brush your teeth or let's get ready for the day.’ I spoke to my husband about it while our son wasn't around. We were both puzzled and a little bit concerned at first. We didn't actually know anybody with a stutter. I have since found out that my dad's brother had a stutter, but he died when he was 22 and I was only two.

Seamus's speech didn't improve whatsoever, and we didn't highlight it. We tried to carry on as normal. Just before he turned six, we had a summer when his speech was really difficult. I rang the general practitioner and had an appointment with a speech therapist about a month later. The speech therapist chatted with him and played a board game. I sat back and watched. She didn't mention his speech to him at all. At the end of the session, she confirmed he did have a stammer, which we already knew. She said she would book more sessions with him and told us about an opportunity to attend two parent workshop sessions.

These parent workshops were really useful as they told us about the structure of the vocal cords and the tongue and how speech works. We take that for granted. They gave us a metaphor of a bucket full of water. When the bucket is full, the water spills out. Some children may be trying to process a bit too much information. Their buckets, i.e., brains, have reached capacity and things should settle. But of course, they didn't. We took him to three or four sessions with the speech therapist and we were told that they probably couldn't do very much more for us at that time.

When Seamus was seven, he was invited to join in with a group of other children with a stammer and they would be introducing the ‘toolbox.’ The kids sat in a circle with parents at the back of the room. We could observe but not take part, probably so that we could learn the techniques and then reinforce them at home. They introduced the toolbox which included around four ‘tools’ including a slide into a word. We were given a laminated sheets with a picture of a toolbox and along the front of it were images that represented each of these four different tools.

I asked one of the speech therapists how they would expect him to remember these. She said, ‘with practice.’ It was like, ‘now you've got the tools so off you go.’ Throughout each of the sessions, he became more reluctant to participate. If one of the participants stammered, they would be asked to say it again. The boys in the group were highlighting when the others were struggling or disfluent. Soon he didn't want to go to the sessions. He would say to me, ‘Why do I have to go? I don't like it. I don't know the boys there. I don't like the boys.’ I remember feeling guilty about sending him. That went on for most of the weeks we went and finally we took a break.

Then he started to develop dreadful secondaries. His eyes would roll, and his head would go back and he would go a funny color trying to force the words out. He went through stages of singing, whispering and avoidance. Then he would say, ‘You tell them Mommy, you say it,’ wanting me to speak for him. When he was around eight, we ended back in speech therapy. She would ask him an open question and he would answer. She made a note of each stammer and

tracked the number of times he stumbled. She would say to him in a really condescending way, ‘Would you like to try that again?’ After three sessions, he was heartbroken at the prospect of having to go again and he begged me not to make him go. He was upset, his speech was worse, and I felt they had just highlighted it. He could barely speak at all now. She said, ‘that’s absolutely fine. That’s your choice.’

Then we read your book. This was about 10 years ago, and it changed everything. But what do we do? How do we help? We still felt desperation. It’s our job to do something. What about the rest of his life? What about his friends? What about school? What about girlfriends? What about everything?

After reading your book, we muddled along for a little bit, but I reread it two or three times. We slowed down our speech and stopped bombarding him with questions. He’s an only child and both of us love him so very, very much. Prior to reading your book, we always asked, ‘So how was your day today? What did you play football today? What did you have your lunch today? Who did you play with today?’ We stripped all that back as we realized that what we were doing was more like interrogating him.

We now realize that we were not ‘not doing anything’ but we had changed the dynamic around how we spoke to our son. Every day we focused on doing things to keep him talking. It felt so much more natural.

We try not to be hard on ourselves. We realize the reason that we did what we did was it was what everyone did. We turned to professionals who were supposed to know better, right? I think they had no training and were just making it up as they went along. It almost feels criminal—these kids have to overcome so much because of the therapy. We still have parents demanding a fix and therapists who are willing to do that. People are not listening.

The “fix it” therapy created more problems—harder problems than the stammering. The sessions that we had initially gone to, the parents-only sessions, were really good and I wish we had had more. Those sessions were so helpful, but they were in complete contrast to the toolbox sessions we had later on.

**“The ‘fix it’ therapy created more problems—harder problems than the stammering.”**

A child is supposed to process a question, formulate an answer, and think about how they deliver that answer—all while trying to remember which tools to use with the sounds they want to make—at the age of seven! It was preposterous. An adult would struggle with that.”

*Michelle, mom to Adam, age 17*

“I knew nothing about stuttering. No one in my family or my son’s father’s family stuttered. When my son started with a speech impediment, to me, all speech impediments could be fixed. I didn’t realize there was such a thing as stuttering as an impediment—everyone stutters. I had no idea it could afflict anyone like it can.

When he was three, we were told that he would probably grow out of it. When he was five, I got a phone call from his kindergarten teacher, and she thought he would benefit from speech therapy. What mother would say no? I thought it was curable. That’s how it all began.

I met with the speech therapist without him and asked her, ‘do we have to tell him?’ She said ‘yes, he doesn’t know.’ Therapy didn’t go into depth at that point, and it was never one-on-one. He was with kids with other types of speech impediments. Then the speech therapist gave me the name of a therapist who specialized in stuttering. At first my insurance denied it because my son’s impediment was not caused by brain injury. It was suggested that we say it was neurological and then it was covered by insurance. I would have done anything for my kid, but not having insurance would have broken the bank.

That’s where you start with the blame factor—especially with no stuttering in the family. Did our divorce cause this? You still start blaming yourself. I continued to believe that this was curable and was going to be fixed. The speech therapist did games, tongue twisters, and easy onsets. I had a chart—different things he could do—like order something by himself, then he would get a prize and stuff like that.

One day at therapy my son couldn’t get a word out. The speech therapist was asking him to read a book. The kid couldn’t talk—he couldn’t say the first word. I don’t think I ever cried about this in front of my son before. The speech therapist stopped and said, ‘the two of you are going to breakdown so just do it.’ My son ran into my arms and we both cried. Then the speech therapist said, ‘okay, now that’s it’s all out, come back and sit down.’ Our son was being taught a lot of things to fix the stutter and very little on acceptance. In the back of my mind, I’m thinking it’s easier for him to stutter than to try and do all this stuff to not stutter. After three years, we stopped therapy as there was no improvement. The fun and games were not so fun anymore, we had to drive into the city, and my son was getting busier with sports.

**“In the back of my mind I’m thinking it’s easier for him to stutter than to try and do all this stuff to not stutter.”**

One summer I started researching speech therapists and I found one that was close. She ended up being the mother of a student I had once had. We saw her for two months but quit because she was horrible! She would have my son put his belly on a ball, lean over, and put a penny in a jar.

This was right before I read your book. This was the summer before my son went into seventh grade. I was already in your group. It was an epiphany that he wouldn’t get better. I cried through the whole book. My child will no longer have speech therapy. I didn’t want to drop the individualized educational plan because of his anxiety speaking in front of the class so we

switched to a consultative individualized educational plan with no speech therapy. The speech therapist would be available if my son wanted to talk. He never did. We then switched to a 504 plan when he was a sophomore.

Today he does presentations in front of the classroom, he orders for himself at McDonalds, he just got his driver's license and also got his student's pilot license. He's done his solo flight and also flew me around the Statue of Liberty. Any yes, he still stutters. He's been in ROTC and was just asked to be the head of a new civil air patrol program in school.

I often wonder, even if I read your book before I put him in speech—which road would I go? What if I read your book when he was in kindergarten, decided to go the route of no speech therapy and he still stutters? I totally agree with the route of building confidence, but would I be beating myself up for not putting him in speech? I beat myself up now for putting him in speech therapy. With so much unknown with stuttering it's hard to make the decision with what's right. You're beating yourself up no matter what.”

*Nadine, age 27*

“I was referred into speech therapy when I was about three to four years old. From what I’ve been told by my mum, it was one-on-one session every four weeks, and they didn’t really do any techniques. When I was seven, she was told by a speech therapist that they actually don’t know much about stammering and over four-years of study, they only actually spend a few sessions covering stammering. It’s mad, it’s crazy—so that point should be gotten through.

My mum took me back to our doctor when I was about eight. We got referred to a center in Liverpool which was a fantastic place for children who stammer, and the speech therapist there just did stammering and nothing else. I attended there once every six weeks in a group session. There it was not learning techniques but feeling confident and learning that it’s okay to stammer. I attended that till I was about 13 and I actually loved it because they didn’t focus on tools. I met others who stammered as well, and I didn’t feel so alone.

**“This therapy was not learning techniques but feeling confident and learning that it’s okay to stammer. I loved it.”**

When I was nine, I got a leaflet to give to my teachers which suggested they give me eye contact and don’t tell me to slow down. My mum would speak to my teachers every school year during primary school. In secondary school, it’s different classes and different subjects and that was a lot more difficult I suppose. I did give out the brochures to those teachers, but they never said anything. It was just brushed under the carpet. For my speaking parts of my exams, they let me record it at home rather than doing it in school.

I remember being concerned for our English exams. We had to do a speaking part and it was a timed 10-minute speech and I was really worried and upset. That’s the first time I realized I am different and I am going to struggle.

Mum—she didn’t get any support, nothing at all. She would take me to the doctor to refer to speech therapy but in terms of ways she could support me, nothing. It was really bad. I think, as a parent, you always want to help.

When I was about five, my speech therapist told my mum to take me to drama lessons. I’m not really sure why, but I did drama for about two years, and I also sang from the time I was eight until I was 16. After the age of eight, I decided to not start anything new so I wouldn’t have to say my name.”

*Neil, dad to Celia, age 10*

**No turning point needed:**

“Our youngest daughter, who is 10, has a stutter. We noticed it about two years ago when she was around eight. She would stumble on certain words, but she didn’t let it bother her. I wasn’t too anxious about it until one of her good friends said, ‘you know when she has that little glitch...?’

Fast forward to six months ago when we were noticing more—maybe because we were doing school from home or was it exacerbated by the pandemic. Nobody knows. Our pediatrician gave us two recommendations. We went to one for an assessment and she came back and said, ‘I can’t help her, but I do know an organization who can.’ She referred us to the American Institute for Stuttering (AIS) which focuses on acceptance, avoidance reduction, and empowerment—for both our daughter and our family. The speech therapist shared her write-up with AIS and that’s how we were introduced to our new speech therapist.

This speech therapist and our daughter have been working with each other for about four months. By and large, I believe it’s been successful. Our daughter is always excited to go on the 45-minute sessions. The first five or ten minutes is usually with all of us and the speech therapist. Sometimes the speech therapist just wants to talk to us separately, and then our daughter on her own.

The speech therapist has helped us with our daughter’s transition to 5<sup>th</sup> grade at another location—all new people. I was concerned about how her speech would be interpreted or accepted. The speech therapist really got ahead of that. She told our daughter, ‘You’re starting a new school soon. We could write a letter to your teachers and also prepare a presentation if you’re comfortable with that. I think you should talk of your stutter with your new classmates.’ The speech therapist prepped our daughter to do her presentation when she felt comfortable. Our daughter came home last Tuesday and wanted to the presentation the following Friday. The speech therapist joined through Zoom at the conclusion of the session and did a Q&A with the class. It was fabulous.

The speech therapist also prepped my wife and I. Prior to starting this therapy, we used to say, ‘say that one more time, slow down.’ It’s great knowing that’s not the way to handle it. While our daughter didn’t seem uncomfortable with that, the speech therapist suggested that instead, we focus on some of the positive things that our daughter does so we can build up her confidence before she goes to school. We want her to latch on to a mindset of ‘hey, this is what I’m great at!’

**“We want her to latch on to a mindset of ‘hey, this is what I’m great at!’”**

We did that the six weeks leading up to school. Our daughter is super smart and we’re never going to have to worry about her in terms of what she wants to do because she’ll just go out and do it. With the support and guidance of our speech therapist, we can help her to be comfortable with her stutter. We want her to feel confident and not go into a muddle because of her stutter.

We’re lucky—we did luck into this approach to therapy. I’m happy that the first therapist was humble enough to pass us on.”

*Karen, age 40 (mom to Betsy, age 11, both stutter)*

“I went into speech therapy around 10-11 years old. I was handed a book by the teacher, and I showed it to my friend and asked, is this me? She said, ‘oh yes, totally.’ After reading it at home in the bathroom by myself, I hid it. The speech therapist was trying to tell me how to talk without stuttering, but those tools didn’t work. Even as an adult, I’ve tried to use the tools. They really don’t work for me—90% of the time. I remember being able to use tools in the clinic. I was confused as to why I wasn’t able to do this in the real world. I convinced my family I didn’t need to go anymore and that was the end of the conversation. I didn’t go back. I clearly still stuttered but no one said anything.

I had a lot of avoidance behavior—pretending to be sick if I had to do a presentation at school, running to the bathroom when we were going around the room making introductions. The therapy was a total waste of time. My parents were so confused. They had three other kids, and we were all close in age. They both had full time careers and we had pets. The whole stuttering thing just flew under the radar. When I would be obviously stuttering, they’d look at me with this weird face like ‘what are you doing?’ I’m a wizard at disguising it.

Hiding it had a huge effect on me. I’m an extrovert and socially I always did very well. I made it my thing. When it came to academics, I didn’t do as well. I wouldn’t put my hand up at school and I avoided a lot of stuff. When I was 25, I got a job that involved a lot of speaking and presentations. At the time I was pretty fluent but as soon as I started this job I started to struggle. I never told anyone at work—yet I was so obviously stuttering at that time. It was stressful for me, but even so, it wasn’t much of an issue in my work.

I still have avoidance techniques. I do things I’m not proud of. When we’re at the pool, I sometimes tell my kids to go tell the man my phone number. It starts with a six and I have a hard time with ‘s.’ I break into a cold sweat—still have that anxiety around it.

I did have to read out my driver’s license number to a woman recently. I stuttered a whole bunch of times throughout it. She asked me if I was okay. I told her, ‘I have a stutter.’ She said, ‘well, good job.’ That was a big move to me—to say it—‘I have a stutter.’

I want to do things differently for my daughter. (Betsy). Parents can have a huge impact on a child’s internal voice.”

*Penn, age 57*

“I started stuttering as soon as I started talking. I became aware of my stutter when I was eight years old in grade three. I found myself in front of a classroom of peers and realized I could not speak like everyone else. It hit me like a freight train. I spent the afternoon after school in my room crying. Mum tried to comfort me, but it wasn’t something I could really process at that point. This was a turning point in my life. Nothing was the same afterwards. It was a fundamental shift for next 20 to 30 years.

The first therapy intervention was when I was 11 or 12 years old, grade six or seven. The therapist was a lovely woman whose name I still remember after 45 years. I would go up to her office and sit in her room and we would go through techniques like prolonged speech. Generally speaking, I could speak fluently in those sessions—trying to hide my stutter. The speech therapist came to my class once, sat at the back and took notes. The teacher got me to speak in front of the class and I was expected to use prolonged speech but since I never used that outside of the speech therapist’s office, I couldn’t do it and found it humiliating.

There were a couple of group therapy sessions where other kids who stuttered came together. One day we went to a supermarket where we were expected to go up to staff and ask where to find something. That was terrifying. There were six or eight of us walking around talking to staff and none of them had been prepped beforehand. One of the staff members asked the kid if he was a slow learner. I told my mum about it and group therapy didn’t continue after primary school.

Socially I always had a tight group of friends around me and was naturally gregarious and outgoing, I’m rediscovering my gregarious and outgoing self these days and that’s lovely. School did not suffer but there were still critical incidents happening daily. I had intense feelings of shame and humiliation. It’s hard to say that therapy increased these feelings, but it didn’t do anything to decrease them. It would have been great to have gotten some guidance and strategies not to become more fluent but to become more assertive. I needed to be actively pushing back against the shame, humiliation, and fear, and find my voice. Some program like that would have been a gamechanger for me.

I was always a writer and many of my adult jobs involved writing, open office plans, telephone calls, and public speaking. It was hard. When I was in my late 30’s and married with two kids, I was on the verge of giving up my job. I was sitting at the bus stop thinking, ‘I can’t do this anymore—this is horrible. I can’t go into an open plan office and stutter My kids are 10 and 8 and what do I tell them? ‘Be the best version of yourself’ and all this hoo-haw?’

It was at this point that I had the biggest epiphany in my life. I asked myself—‘what’s your definition of a good day?’ I was horrified by my answer—my good day was one that I didn’t stutter. It was a terrible realization. A good day was defined by the absence of something, not by the presence of something. That hit me as a gross failure on how I was living. I knew I was failing at the task of creating a life.

So, what do I do?

The answer came to me almost immediately. What happens if I turn it 180 degrees? What if, from now on, my definition of a good day was one that I DO stutter—especially in front of a stranger? I had to change the way I saw myself, the way I saw the world, the way I interacted with the world. It was terrifying.

**“What if, from now on, my definition of a good day was one that I DO stutter—especially in front of a stranger?”**

It took me a couple of days to work up the courage, but finally I went up to somebody at that same bus stop and asked them which bus I needed to catch. Mind you, I had been catching that bus for eight months. That was exhilarating—chills, spine tinkles, incredible sense of power and wellness. I collected myself, walked away and gave myself a subtle pack on the back. I had done something very simple—at the same time I was volunteering to be put in danger by deliberately putting myself in that position.

My goal was to, every day, go up to a stranger and ask which bus to catch or where the peanut butter was in the shop. There were days when I didn't feel strong enough, but every time I did it, I felt wonderful. It was a constant affirmation. I didn't notice any major changes to my fluency for the first six-nine months—then I did start notice I was being much more fluent in situations.

I had joined Toastmasters and was giving speeches regularly. In 2013, I trained to become a public speaking coach. Now if you told me there were 500 people around the corner waiting for you to give a speech, I'd say 'see ya Dori, I'm there.' It's turned from terrifying to exhilarating. That little switch, terrifying to exhilarating—once you find a way to flick that switch, it's great!”

*Phillip, age 67*

“I began to speak in single words at the age of two, but after a number of months, simply stopped talking altogether. At the age of three, I decided to rejoin the world of oral communication, resumed speaking, and started putting sentences together for the first time. I also started to stutter. My first speech therapy (the first of dozens of therapies I’ve tried) was around the age of three or four. All I remember is a pointless exercise she prescribed for me to practice at home—blowing bubbles in a glass of water with a straw.

My stuttering was a sore point for my kindergarten teacher. She told my parents during parents’ night that my stuttering plus all my other ‘weaknesses’ were a clear sign of mental retardation. My father pointed out that I was reading the New York Times and his law books. In addition, by the first grade, I was playing C.P.E. Bach's Solfiegetto accurately and composing my own music.

Another type of therapy I began at the age of four was through a youth guidance center—and this lasted for about six years. I remember talking about the activities I enjoyed, such as composing music. One day I noticed my therapist desperately writing down everything I was saying including all my stuttering moments. Apparently, she needed this for some type of evaluation. I corrected her frequent errors in notating my stuttering, but I found this experience quite humiliating.

In sixth grade I was asked by the teacher if I would prefer to do a written report rather than the oral one required of the other kids. That’s what I liked—being given an option. I told him I would do it orally like everyone else.

As a high school junior, I finally found a therapy that had some value (in a limited way). Using techniques based on Charles Van Riper’s writings, I was able to substantially reduce the lengths of my blocks—which had been recorded and measured up the 45 seconds long. I was still blocking on most words, but now I was practicing to release blocks with reduced tension rather than force them out with more pushing.

**“I initially had some success, but eventually my speech fell apart and that was devastating.”**

As a college senior at age 21, I had my first experiences with a fluency-therapy program, the first of four fluency shaping programs I would become involved with over the years. These programs included Gradual Increase in Length and Complexity of Utterance (GILCU), and the Precision Fluency Shaping Program of the Hollins Communications Research Institute. I initially had some success, but eventually my speech fell apart and that was

devastating. I just couldn’t maintain consistent target fluency for more than several months at a time. I wasn’t able to maintain the long-term intensity needed to make the fluency last. It was very frustrating.

In 2000, at the age of 46, I married my lovely wife and moved to her homeland of Norway. Not long after this move, I pulled the plug on my chase for fluency. I was tired of the enormous effort and years of exasperation, all the ups and downs of fluent periods and relapses, all that intensive practicing and focusing, trying desperately to become a fluent person year after year. It was now

time to enjoy life and settle back. If I happened not to be the most fluent person in the world, well, so what? I am no longer pursuing a dream of fluency of speech. Instead, it's a dream of fluency of life. And guess what? Dreams do indeed come true!

*Rory, age 58*

“I think I was aware of my stammer when I was maybe four years old. I remember asking my mom and dad, ‘How long will I have this? What can I do to get rid of it? Will it just go away?’ I wasn't really pleased with the answer because no one was able to give me an answer.

When I was eight or nine, a teacher suggested I use expression when I had to read out loud. That year I was able to read easily enough because I was being very expressive when I was reading. The next year, I remember going into the classroom and being asked my name. I had a massive block, and I was quite disfluent that year.

I was lucky in a way because I was quite good academically and also good at sports. I was able to achieve at these things even though I had this disfluency. I used to get nervous and anxious and then embarrassed when we went around the classroom taking turns talking. You go through all of those emotions when the whole class is listening and you're not going to get the words right.

My mum took me to a speech therapist when I was about eight or nine. I didn't enjoy it. I didn't want to go. I felt embarrassed and ashamed and didn't want anyone to know that I was having to go to speech therapy. I remember playing Snakes and Ladders and my aim was to win because I was quite competitive. My mum told me that the speech therapist would record me speaking or reading and it reached a point where I was completely fluent during therapy but not outside of therapy. The therapist told my mum, ‘I don't know what else I can do. I don't know why it's not translating to outside the sessions.’ I probably tried really hard to not stutter while there because I was so competitive.

I initiated a return to speech therapy when I was 17. At that stage I was really trying to help myself. I can't remember the technique—maybe it was using softer contacts and slowing down the rate of speech. I got more out of it then because I was a bit older, and I had initiated it myself. I was also asking more questions as to why I had this and other people didn't. Why did it happen with me?

**A turning point:**

When I was 19, I started university to do medicine. I was anxious because I knew there was no avoiding my stammer. It was at that time that I decided to do a week-long intensive course for stammering that emphasized non-avoidance. We would go out on the street and introduce ourselves to strangers and maybe tell them we had a stammer. The big learning I had, more than using any methods, was learning to overcome the embarrassment and be open and not scared about it. After that course, I began talking about it with my classmates and people that I knew, and I was a bit more at ease with it.

**“Becoming more open about my stammer let out a lot of the emotion and actually improved my fluency.”**

For many years I felt that I had to get rid of this, that I had to cure it. On one hand maybe I didn't try hard enough (laughter). On the other hand, becoming more open about it and being able to

talk about it let out a lot of the emotion around it. Acknowledging that it's an aspect of me made it easier to live with it. It also improves my fluency because I was becoming less anxious about it. Now when I'm in a meeting and I begin to block, I openly explain that I have a stammer and they might have to wait while I get my words out.

I went to Liverpool in my mid-20s and linked up with the British Stammering Association. I met a lot of other stammerers who were quite motivated. It was a good connection, a good group to be involved with. I was able to share my stammering experience with other people and be in a room where I didn't have to worry because everybody was in the one boat. There were people there who had achieved a lot as well. There was a liberating aspect to that, a real positive.”

*Serena, age 35*

“I remember my first time taking speech therapy. I was enrolled in a private school, but speech therapy at the public schools was free. Insurance wouldn’t cover private therapy and my parents would have to pay really high fees out of pocket. Every Wednesday Mom took me to the public school for speech therapy. From what I remember it was a lot of slow speech and prolongations. I didn’t have any negative thoughts about going to speech because it wasn’t at the school, I went to so none of the kids knew me. I never had to get pulled out of class. I know a lot of people have a negative connotation because of that.

The speech therapist kept telling me to go home and practice and I never practiced. I mean, I was five. This was something I was supposed to do, should be doing. I’m pretty sure that the morning of the therapy I would frantically do whatever homework I had been given only because she gave me some sort of trinket. When I was with her I was able to use the techniques—I can do techniques really, really well when working with a therapist. It’s in the outside world where I can’t use them.

After that I didn’t do much stuttering therapy. My mom took me to my first stuttering conference when I was 12. A part of me really hated watching other people stutter. I knew that was weird, but I was trying to distance myself from the community. As soon as the conference finished, I remember saying to my mom, ‘well, I’m not like them.’ Seeing people stutter made me feel shame so I wanted to distance myself further. I wasn’t analyzing it that much at that age—but a part of me knew that wanting to distance myself from those people wasn’t great.

By high school, my stutter became severe, and I didn’t talk near as much. On top of the teen angst, I felt isolated. I didn’t do speech therapy again until I went to college and received therapy from a speech therapist student on campus. There were no big changes in my speech. After college I decided to go to graduate school because I was afraid to go out into the world. If I was in a very high-stress situation I couldn’t even get words or sounds out, so I figured I’d just stay in school. I could kick myself for that a million times now.

**A turning point:**

While in grad school, my teacher said, ‘your speech is a problem.’ I agreed. That’s when I started seeing a therapist focused more on acceptance and avoidance reduction rather than speech tools. For the first time the goal was to become comfortable with myself. This approach to therapy helped me to change the way I think about myself as a person who stutters and as a speaker overall. They helped me to validate my opinions by saying them. Big changes started to happening when I learned about positive restructuring. These therapists helped me to get back to a steady place and undo a lot of the fluency shaping angst that I had learned.

I’m super happy that my journey led me to this therapy approach because it’s changed me as a person overall. It’s given me the confidence to put myself out there. Now that I don’t have the pressure to be fluent and my stutter is just accepted as an accent or way of speaking, I produce better work. I can come to you not worried about what I’m saying. Well, I always worry about what I’m saying having nothing to do with stuttering.

I’ve become an online influencer in a field not related to stuttering at all. This means I’m constantly explaining to people, hey, I have a stutter—so I’m talking to people who don’t stutter and normalizing stuttering in a non-stuttering setting. I love that I’m big in this field that has

nothing to do with stuttering. Thousands of people watch my insta-stories and I stutter in all of them. People message me with ‘that’s a great point’ not with ‘I can’t understand you.’ If you can find something you care very strongly about, your speech won’t be an issue.”

*Sheila, age 34 (also a speech therapist)*

“I was five years old when I started stuttering—pushing the words out with a constipated look on my face. My father stuttered and had enormous amounts of shame. He did a lot of work in his lifetime to get rid of it—it was his mission. He didn't want to get me speech therapy because he really didn't believe in any of the traditional approaches as they had never worked for him.

The truth is, in some ways I'm happy that he didn't send me to speech because I probably would have gotten this sort of smooth, bumpy traditional thing that everybody else was doing at the time. Back then, they weren't talking about acceptance the way they talk about it today. That was the good part, but the negative part was that my father was like my speech therapist and he wasn't really doing a better job. As an adult, he learned an airflow technique that he practiced each day—for at least an hour. He started training me in this airflow technique along with a constant hand motion which was meant to tell me to slow down. As I was growing up, this was a constant motion. Slow down. Sometimes it was one hand, sometimes both hands, and sometimes he'd use words. Most of the time it was just the hand.

This all solidified in my mind the notion that getting rid of the stutter was the goal and we would pursue that goal together. His mission became our mission. At the time it made sense to me, because I was indeed frustrated that I couldn't get my words out. Instead of seeing the stuttering as a problem to get rid of, I wish we could have had a conversation that yes, this is something in my life...and it's okay.

I remember feeling irritated because I didn't feel my father was ever listening to what I was saying. The only way my words and my communication was acceptable was if I slowed down and got through it without the struggle. That was the only way he would finally listen to what I was saying.

**“I felt like I was born flowing and spontaneous and then got smacked for being who I was.”**

I felt like I was born flowing and spontaneous and then got smacked for being who I was. I was a very expressive child but once that hand was used to tell me to slow down, I felt like my flow and my natural child's purity got intersected and things were never the same. I began to question everything. I went along with it because I just wanted to please and play. I wanted to see the smile on my father's face when I did it the 'right' way—like a dolphin wants to please its trainer.

Children need space and encouragement to express what they're feeling. I remember the first day of first grade. The bell rang and everybody went inside. All of a sudden, I was scared to go inside. I stayed right outside of the door. I just stood there. My teacher came outside and said, 'the class has begun. Do you want to come in?' I said, 'no.' Then she said, 'You know what sweetie? You can wait out here until you're ready to come in. You don't need to come in right now. It's fine.' She was allowing me to stand outside the classroom until I was ready to come inside. I'm sure she had a plan to check on me but after a few minutes I was ready and walked in. That time and space was such a gift and made such an impression on me. So special. This is what I needed. I needed presence, I needed patience. I needed to be told that I'm okay just the way I am... Stutter and all.

In middle school and high school, I was terrified to stutter. Terrified. I was terrified to raise my hand in class. I was terrified to engage in group conversations with girls in my class. My brain started developing these different techniques to avoid stuttering. I also came from a broken and abusive family and had lots to hide besides my stutter. It was a big school, and I was one of those children who fell through the cracks. There were some teachers in earlier years that knew I was going through a hard time because child protective services were called on both of my parents several times. There was one teacher who told me that if I ever wanted to talk, she was there for me. I never did, but it meant a lot. I was obsessed with finding ways to pass as ‘normal’ person, and that included being a fluent person.

Towards the end of high school, I was looking through a list of possible careers. I did not know what a speech therapist was, but a friend told me it was working with kids and that resonated with me. I also believed that this would be my chance for someone to wave their magic fairy wand in my face and get rid of my stutter. I was like, ‘Oh my God, this is gonna be great, an answer to my prayers. My stutter is gonna go away and then I’ll be able to help others!’ That was my big fat dream and fantasy, but it did not happen.

In grad school, I started to pick up on a sense of secrecy and shame felt by many speech pathologists because they felt like they should know more about stuttering. I felt like I needed to pretend that I had the answers. We need to be able to say ‘hey, I’m a speech therapist who doesn’t know a lot about fluency and stuttering and that’s okay.’ Even the fact that it’s called ‘fluency’—would we called a deaf class a ‘hearing’ class? I don’t think so!!

### **A turning point:**

Early in my career as a speech therapist, I had a student who stuttered. I was teaching him techniques because that’s what I knew. At some point I realized that he had some shame around his stutter. All of a sudden, I felt completely frozen because I realized, ‘Holy, holy moly. I don’t know how to help this boy; I don’t know what to do!’ Then I realized that I didn’t know how to help him because I did not know how to help myself. I had no idea what to do about this shame that I had around my own stutter. Can I really do my job if I can’t help myself?

That’s when I learned about the National Stuttering Association (NSA). In my first meeting, everyone was talking about acceptance and authenticity rather than about their sucky stuttering. I was like, ‘Where am I?’ They told me that there was one thing they wanted me to do—and that was to talk and talk and talk, however it comes out. Connect with as many people as you can and yes, it’s okay to stutter. This was such a contrast from the world of avoidance that had plagued me my entire childhood.

Things really started to change for me when I went to my first NSA conference several weeks later. All of a sudden, I’m meeting all these people who have gone through the same types of avoidance experiences and I wanted to hug them. I found my tribe. I often thought that if I didn’t stutter, I could rule the world. I would be the most popular kid in the world. I would raise my hand at a million times in class. When I decided it was really okay to stutter, I had no excuse anymore. Now I needed to actually do life. I felt like was given a second chance at life.



*Sheryl, mom to Julia, age 10*

“Our daughter’s stutter started overnight at three with blocking and repeating. She said, ‘I don’t know what’s happening, I can’t speak anymore.’ We went with it for a bit but it was bothering her, so we decided to look for a speech therapist.

Our pediatrician recommended a speech therapist who had experience working with kids who stutter. Our daughter liked her right away. We did Lidcombe from when she was four until seven. With Lidcombe, we had to count five praises and one correction. We would do it when we were at home with her. Our daughter was praised for smooth speech and the speech therapist would press a button every time she had a block or repetition. She would then get a score at the end of a therapy session. Gradually we noticed an improvement in her speech—she was able to get to almost no stutters and it did carry into her day-to-day life—for a bit.

The stuttering would always come back, and we couldn’t find a pattern. She would be very disfluent at home, grimacing and trying to get words out. We’d say ‘omg, she’s going to be so bad in her session today’ and she would score the best score since the beginning. She was getting conditioned to speak smoothly during the sessions. The speech therapist would say ‘omg, she’s making so much progress’ and we’d say, ‘but she’s not really making that much progress because at home and daycare she’s still stuttering quite a bit.’ It was frustrating.

The speech therapist kept telling us that after a child is six, it’s no longer about fixing the stutter. It’s about learning how to live with the stutter. At age seven, therapy shifted to how to recognize when she’s going to stutter and develop strategies to manage it. When she felt a stutter coming on she was instructed to pause, take a deep breath, and then try to say her words. I work full-time and so does my husband so my mother, who is retired, would bring her to the appointment. Even my mom found that our daughter would be very smooth during these sessions but five minutes after the session she couldn’t tell Grandma what she wanted in the store. My mom thought it was very strange.

My mom continued to work with Julia, but it got to a point where Julia was getting so frustrated. Here was her fun time with Grandma being overtaken with this stressful therapy that she didn’t like. We also noticed she was withdrawing and talking a lot less and becoming very frustrated with herself. One day she was practicing a class presentation in front of us. She was struggled so much she fell to the floor crying and saying, ‘how come I stutter? Am I going to live like this the rest of my life?’ Once that happened, we stopped the therapy because quite honestly, we didn’t find it was helping anymore at all. We stepped back from therapy and then I found your book and I loved it. It’s almost painful to read because you have this desperation you want to help your child.

**Here was her fun time with Grandma being overtaken with this stressful therapy that she didn’t like.**

#### **A turning point:**

Until I found your book, I felt so alone trying to find something that could possibly help. If I had your book to read back then, I would have made different decisions with better information. I assumed that the speech therapist was the expert in speech, but she never mentioned resources. She almost wouldn’t even acknowledge what we were saying about our daughter stuttering at home but not in therapy sessions. There was no discussion about that.

Now that she's 10, something that has happened in the past year—she basically decided that yes, she stutters and she's not embarrassed about it and if people ask, she says, 'it's a stutter and I've spoken like this since I was three' and they're like, 'oh, okay.' She has a really supportive class this year. There are some kids who have made fun. The group of girls she spends time with are so encouraging. In the past year we've focused on getting her comfortable and encouraging her to talk whenever we feel she's pulling away.

She loves drawing. She's really athletic—runs all over, swings from monkey bars, she has endless energy and loves to dance. We put her in lessons once, but she didn't want to continue with structured dance—she wanted to dance on her own terms. She has so much character and is so loving. She's full of life.”

*Ted, dad to Jonas, age 22*

“Jonas locked up and got so stuck on words. He’d get stuck on ‘d’ for daddy and would be so driven to frustration that he would bang his head on the floor. We would tell him to slow down, take a deep breath, go slow. He struggled into elementary school—almost to the beginning of high school.

One therapist had him trying to pick words he wouldn’t stumble over—turning him into a living thesaurus. If I asked a question, Jonas would stare at me because he was picking his words. I would forget sometimes and lose my patience. I had seven kids all clamoring for dinner. His siblings didn’t make a big deal out of it. They did stick together and protected each other.

**“One therapist had him trying to pick words he wouldn’t stumble over—turning him into a living thesaurus.”**

I wish there was more of a total family meeting as far as tactics to see what works. I felt like I was in the circle game—by the time I’d get the information, it was different. Also, the direction changed—I didn’t always understand what or how they were trying to accomplish things.

I’d share videos of famous people I came across (actors, newscasters) who were able to control their stutter well enough to make a living with their voices. I thought that would be motivational but I’m not sure it really was.”

*Trudi, mom to Clare, age 11*

“We were not educated about the different approaches. When we started out, I didn’t know anything about it or that there even were different approaches. We just did what the therapist said.

First the therapy was special time at least five minutes a day which was actually a lot harder than it sounds. It was one-on-one, slow type of game, or play with her dolls or do a puzzle but no pressure on her to speak. We were to acknowledge what she was saying, follow her lead, use good eye contact, listening, responding, etc.

I don’t think she knew it was about her speech, not at first. They did say you shouldn’t keep it taboo. If she is stammering, you can say ‘it was a bit bumpy.’ When I’d say that, she’d say ‘ya I know my speech is like that—so shut up.’

We did get a different stammering therapist for two or three years. We carried on with special time, and the new speech therapist talked about the iceberg\*—and also did a tool kit. Our daughter was okay with it, but she would ask, ‘when can we play a game?’ She didn’t really want to do the tool kit stuff. We stopped because she was getting on well.

She was about seven or eight at this time. She attended a group therapy by the school and there were only two who stuttered. They started talking about the techniques like sliding into their words and breathing and that sort of thing and she got upset. She started feeling like she hated the way she talked. She went in feeling good about herself and left feeling rubbish. I think the message is a bit ambiguous—on one hand you’re saying stammering is okay but on the other hand here are some techniques to use to not stammer.

**“She started feeling like she hated the way she talked. She went in feeling good about herself and left feeling rubbish.”**

**A turning point:**

She is now 11 and just finished group therapy—eight weeks on Zoom with two other kids her age after a break of about two years of nothing. The therapist in the latest group was apologetic about her earlier experience and admitted the other therapist wasn’t well-qualified. She did have a better experience the second time around when they didn’t use speech tools. It was all about building self-esteem, self-confidence, and talking about communication. She quite enjoyed it.

Her speech has fluctuated so much from really stammering a lot to going down to nothing. I could never see a pattern in what was increasing or decreasing her stammer. She knows if she wants to bring it up, she 100% can. I did see some writing she had done in the latest group session—she said, ‘I don’t like it when Mom says stuttering is okay.’ She’s probably thinking, ‘go away, you don’t know what it’s like to stutter.’

During the journey, she has had time when she felt shame about her stammer. She went silent for a period of time and would point at things and do sign language. She was more quiet. I remember feeling a bit panicky and I think that’s when I read your book. I was worried that she was going to stop talking and she seemed sad.

She loves drama, dancing, art, singing, but because of Covid she hasn't been able to do dancing or drama. She hates the Zoom drama. She enjoys school. She has lots of friends. Next year it's a whole new school so she's going to have to start from scratch. She has done a couple of presentations to the class. I'm not sure if she'd do it now. I talk to all the teachers in advance, so she gets an equal opportunity in the class but it's up to her whether she wants to tell her classmates. I tell them they need to give her time to reply because sometimes she blocks, and people think she's just not talking. Don't make her speak in front of the class if she doesn't want to but don't assume that she doesn't because sometimes she does.

It takes a lot of energy to hide her stammer, to change words, to use a higher voice. She tries to control it to a degree. It's people's reactions. You don't want to see the reaction in their face. At seventeen, I had panic attacks when I'd have to read in front of the class. She's been a role model for me, speaking up in class.

I've learned a lot by joining the stammering groups on Facebook, hearing from other parents, and from reading your book. If parents don't know what the options are, they're not going to go looking for them.

I needed reassurance that what I was experiencing with my daughter was basically normal—fluctuation is universal and there's not a solid reason why. I do get the feeling from the therapist that they have no clue. I felt I was the only one saying I didn't know what made it worse or if there was a pattern. 'Oh gosh, I have to find the pattern. What's wrong with me?' She stammers more at home; I got the feeling it's because I'm not listening enough but is it because she's more comfortable? She recently said she would know if the new therapy group had benefitted because she would stutter more because she would feel more comfortable.

I wish she would have gotten more on building self-esteem. There was no support for me either—how to keep things calm for her. I don't know what they could have offered, what I would have wanted. It would have been nice if they would have offered me your book. That would have been great, to be honest. It would have been good if the therapist would have reassured you more that if you do stammer it's not the end of the world.

They said research shows if we didn't deal with speech right away then we would not be able to get rid of the stutter. That's just not true. If my other child started stammering, I wouldn't rush to a speech therapist right off."

\*<https://www.stutteringhelp.org/blog/sheehan-stuttering-analogy>

*Tykeria, mom to Dacquan, age 14*

“Dacquan started having speech issues at age two and a half. I took him through the public health system for an assessment when he was three. At that point, I probably understood maybe 50% or 60% of what he was saying. I don't think he was stammering yet; it was more just articulation. We were told that this was all normal disfluency or normal articulation for his age and to come back if we continued to have problems. I'll admit, I felt a little bit dismissed.

Over the next year and a half, he began to stammer and I could only understand him about 15% to 20% of the time. When he was five, I took him back for an assessment and the speech therapist noticed both fluency and articulation issues. He was sent to therapy through the public system, and he was also referred to a private therapist.

**We were told that this was all normal disfluency or normal articulation for his age and to come back if we continued to have problems. I'll admit I felt a little bit dismissed.**

The private therapist was amazing. I was getting so distressed at my little kiddo who was stammering and beginning to have a lot of tension. He loved seeing her. There was a lot of parent coaching—slowing down our speech turn-taking. Dacquan's stammering basically settled down and his fluency really increased.

The private therapist felt he was doing great with his stammer, but she was still seeing articulation issues. She referred him to a speech therapist who focused more on articulation. It was supposed to be for just four to six months, but it stretched out to four years. That just went on and on and on.

In the meantime, I began to see how familial stress was impacting his speech. My husband and I separated and were divorced, and the kids were going back and forth between the two of us. I began to notice the stammering begin to reemerge and he began to hate the speech therapy. I put feeler sentences out to the therapist about things being tough at home, but none of the broader picture and the stressors it caused was really ever picked up on. The therapy itself became a massive stress.

The stammer was totally ignored by that therapist, which is probably good because she didn't actually try to intervene for that issue. I was starting to wonder if what we were doing in therapy was impacting the stammer. A connection was never made. I felt it was basically implied that our son wasn't working hard enough. There was this kind of fault implied. At some point I decided this was crazy. As a parent you try so hard, and his stammer only got worse.

### **A turning point:**

He and I decided we're going to stop with this speech therapist, and I asked him about going back to the private therapist. He agreed. Oh my God, what a relief! He loved talking to her and she got right into the bigger picture of what was happening in his life. It was really a mix of counseling along with the speech therapy knowledge and it was an incredible combination. She also touched base with me to provide counseling and support. It was an eye opener for both of

us. It became clear to us that the impact of everything going on in his life was dramatically impacting his speech.

She touched on some techniques to address the physical tension and she also touched on emotions. It became clear to both of us that the emotions were the main avenue to pursue. He was a teenage boy with lots of testosterone flooding and system, displaying a lot of irritability and anger. He needed help reaching the place where he could, without denying or suppressing all of those emotions, remain functional, especially in his communication. She presented several fluency techniques as something he could experiment with, but it was not a primary focus. All of her therapy was very playful and respectful. That led to him to feeling that this therapy was a safe space for him.

Our private therapist brought both me and his older brother into the conversation and that was invaluable. So much of our younger son's interactions were with the two of us as a family unit. We learned to slow our speech down and incorporate some pauses. It helped tremendously from a therapeutic point of view. If there's a shift to a more positive therapy and approach to stuttering, this won't just be for the child. The impact is going to be for the family unit and will spread into the schools and our communities.

I can't understand how speech therapists cannot address a child's family life and circumstances. Stress affects your body. Even if the therapist is not trained to be a professional counselor, they could just ask how it's going at home and be a good listener. Another thing, and this could make me cry, when a child reaches a point where they hate therapy, why don't we see that as a guidepost or an alarm signal rather than the fault of the child? I felt like I had entered a bit of fog when my brain said, 'I'm supposed to be trusting the speech therapists, they are trained,' but my heart started to feel that this was not okay for my child, and he really didn't like it.

I feel that the work our private therapist did with us goes far beyond those sessions. Her sessions are so small compared to the impact of what she's taught and modeled for me and my family unit. Then the impact becomes over a bazillion number of hours, instead of just the half hour of therapy exam. That is true power because then you're exponentializing the impact.

Stammering isn't just about communication. It is about connection and for the child in front of us to be able to communicate their needs, wants, dreams, and ideas. Connection should be the number one goal of the speech therapist's role with the child. I do become furious as a parent and a family physician, to think that we do any kind of therapy that causes our children to experience and internalize shame. It can destroy their self-worth and self-value and they end up having to deal with this into their teen and adult life. The #1 tenant should be "do no harm, right.?" Especially with children. They're so vulnerable."

*Vicky and Andrew, parents to Noel, age 10*

**No turning point needed:**

**Mum:** “We first detected a stammer when Noel was four. He had been a late talker and I didn’t want to discourage him from speaking so we didn’t address it at that time. When he was nine, he told me he was having trouble saying his name and there were other sounds he couldn’t say. We had heard about an organization providing parent child interaction therapy for stammering children so we self-referred and went through the assessments, which were quite rigorous.”

**Dad:** “From the first meeting, they told us the severity of the stammer wasn’t their main interest. It was the impact the stammer was having. They explained that some children can actually have a very pronounced stammer and not care one jot about it. Our son’s stammer was very mild, and even though he was starting to be bothered by it, we collectively agreed that at that time it wasn’t bothering him enough to pursue therapy which would have required extensive travel and disruption for 10 weeks. They told us that we could always get in touch if things changed.”

**“From the first meeting, they told us the severity of the stammer wasn’t their main interest. It was the impact the stammer was having.”**

**Mum:** “That was in January of 2020. Of course, the lockdown came in March and our son’s stammer actually improved during this period. In September, we noticed a deterioration once he started back to school. This was also the first year at school whereby they have subject teachers. Before they had one teacher who taught them everything. Now he had a different teacher for every single subject which meant he was having to introduce himself every time. Our son then asked to go to therapy, so it was an easy decision because it was driven by him.

In December 2020, we started a course of 10 weekly sessions with The Palin Centre for Stammering and their parent child interaction therapy (PCIT). Each session was an hour long and we loved it. It was perfect. I was afraid of it ending and being let loose, but what we learned during those 10 weeks was incredible. For the first three weeks I was skeptical and just going through the motions. I didn’t fully understand why we had to be there.”

**Dad:** “You’ve jogged my memory. I knew that people often feel that if they talk more about the stammer, it really becomes a thing. This was something that worried me. People never noticed that our son had a stammer and now we were going to keep banging on about it. Was it going to be self-fulfilling? He clearly had a stammer and was quite upset about it. Our speech therapist addressed this right at the start. They said that people often think that if they open that can of worms, it’s going to get worse because you’ve put a label on it. There’s still a little part of me that thinks that the snowball runs and by putting a focus on it, it can become a much bigger thing, but they did put that right up front.”

**Mum:** “They talked about the fact that parents don’t cause stammering because we quite naturally started to think, ‘what have we done? How has this happened? Is it because we did this, we said that, we shout too much?’ or whatever. They were kind of myth busting and just trying to bat away the reservations one might have.

They told us right up front that we were both important in this process and the three of us would be involved in the therapy. We were both surprised by that, but we've clearly come to understand why that's so important. We've seen the value in being able to work together through a range of exercises. There was very little about mechanical techniques with a bit on tools and how the voice works. Our son was quite responsive to this because it made sense to him. They also looked at our perception of the environment, anxiety, and a whole host of more psychological aspects. I think a lot of that played a bigger part than thinking about relaxing your tongue when you talk. It was much more about the bigger picture and that made sense to us.

We did special time where each parent individually spent just five minutes, a minimum of three times a week, with our son doing something that he wanted to do. We individually had our own communication tasks and targets. Targets focused on managing questions, interruptions, and letting our son take the lead during this time.”

**Dad:** The idea was to do some sort of activity that didn't involve a screen and didn't involve moving around or going outside. So, Lego, chess, cards, jigsaw puzzles, things you can both be quite absorbed in. You're naturally communicating with an awareness of your weekly target. When I did it with our son, we would quickly talk about our targets and I found it quite hard to not just go into automatic mode. I know our son often said he forgot about trying to do his targets, but even just the fact that you briefly spoke about them was helpful. After five minutes the special time was finished but we could continue whatever we were doing with no need to worry about targets. Having that focused five minutes of being aware of how you're communicating in terms of the thing you want to work on was helpful. We also made an effort to have special times for our youngest so that was quite a lot of that going on, which I don't think we expected.

We would meet up once a week with our speech therapist and talk about our special time—each individually. ‘What did you notice in yourself? What did you notice in your son?’ I felt after six or seven weeks, that became a bit repetitive. Our speech therapist said that you can start to let go of it and just bring that same awareness to your ongoing communication as it's meant to integrate. It's easy to forget that so the special time just reminded us to have that focus.”

**Mum:** “I really enjoyed learning about the stammering iceberg\*. One of our tasks for homework was to watch two videos, one was from the British Stammering Association and one from the Stuttering Foundation of America. Young people and children were being interviewed and hearing people talk about their experience so bravely and so openly was very moving. At the same time, I was scared. Our son's stammer is mild, and I didn't want him to feel that this was how other people saw him because his is not pronounced.”

**Dad:** “I agree but I also beg to differ. Sometimes he can get quite a pronounced stammer at home. He just doesn't do that in public—he avoids it. The videos demonstrated an openness—maybe those children got to a point where they were so okay with it that they didn't bother to try and cover it up. It was a hard watch. How do people see our son? How does he see himself?”

**Mum:** “It was hard, but we had to watch it. I became more aware of certain things that I mustn't be hard on. This was hard because I have certain standards—that sounds pompous—but I have

certain ways of how I believe things should or shouldn't be. It's very hard to give that up but I'm learning to soften.

As we were coming out of the lockdown, we decided we were done with extra-curricular stuff apart from football. Then our son announces that he really wanted to do a new activity called Podcast Club. We knew that would be so good for him, especially for confidence, so we said OKAY. At the same time, we found out that his headmaster has a stammer which was an amazing revelation. One of the tasks at Podcast Club is that you interview either a member of staff or some external party, and the kids have to prepare a few questions they would like to ask. One of the questions that our son wanted to ask his headmaster was if he had any tips for stammering? He sent the question to his Podcast Club teacher and said, 'I'm going to ask this question because I also have a stammer.' That was the first time he ever said to a group of people that he had a stammer. That was a big deal."

**Dad:** 'When we would meet up with our speech therapist, we'd talk about things we were pleased about that week. This was designed for our son, but we all had to go through it as well. Sometimes our son would say things that I certainly hadn't been party to prior to therapy. For example, once he said, 'oh, yeah, in French, I knew the answer and I put my hand up and answered the question. Whereas before, I would have just kept my hand down.'

Then our speech therapist would make suggestions like, 'maybe next week you could talk to your friend.' If he was uncomfortable with it, he would not do it and the speech therapist was fine with that. I got the impression that talking about it is easier with people he doesn't know that well. With very close friends, he's a bit more protective of how they find out or how they know about it. So, the openness was a big part. Another big part was focusing on anxiety. That was a very big characteristic of our son, worrying about things and being anxious. That was put up front and our speech therapist recommended that we seek anxiety management support.

With parent child interaction therapy, we find his speech much easier to talk about and much easier to work on—not fix—but just work with. We've had conversations around everyone having their thing. We can't see everyone's thing, but stammering is your thing, and you have to own it. It's not who you are but it's part of you."

**Mum:** "I am realizing that we're very spoiled because the parent-child interaction therapy is the only therapy we've known. It just fell into our lap and is free to access. It had been recommended off the cuff when our younger one was having a bit of a speech issue, otherwise I would never have known about it. To hear you say that this is not the norm makes me feel incredibly lucky and blessed. I feel like our speech therapist is part of our life and we've gone through amazing moments—both wonderful and dire—and we would say, 'oh, we have to tell our speech therapist this.' It's all of us together. Our therapy was a family thing."

\*<https://www.stutteringhelp.org/blog/sheehan-stuttering-analogy>

*Willow, mom to Jack, age 8*

“We did therapy for almost a year, but we don’t to therapy anymore. In Australia all that was offered was Lidcombe. There’s all this research and you want what’s best for your child. I had this free therapist—a child speech therapist trained in Lidcombe only.

Our son didn’t mind going to the sessions at first. She made it fun with games, books, and crafts. She was a lovely person but intuitively it didn’t feel right. The idea of praising him when he spoke without bumps seemed ridiculous. I was praising him for something he did with no effort. It seemed very fake to me—praising him for how he spoke. Then he really started to not like it. Partway through the program we’d notice the bumpy words and I would point it out and it felt awful to criticize him for that bump.

I also started hating the talk time sessions every day. When we were doing Lidcombe, I was highly in tuned to when he was stuttering. Now I hardly notice, and I quickly move on. It built my stress up and up—to be so focused on his stutter. Some days he stuttered more and some days he stuttered less but overall, it stayed the same.

**That was the idea of Lidcombe—you have to get it in this little window. It was so much pressure and I felt like such a failure.**

**A turning point:**

In the end, the therapist said she couldn’t fault me as I was following the program. She could see that nothing was happening for us and felt we should just leave it. I had also just discovered your book. I was hesitant to let go of the mainstream therapy but when I read your story it gave me another way—it was such a relief. We

homeschool and we didn’t choose that because of his stutter. He went to school, and he hated it. We were able to have him home so that’s what we do. I’m glad he doesn’t have the whole school social dynamic thing to contend with. He has friends out of school but he’s not a big social person anyway. He doesn’t seem very conscious of his stutter and doesn’t have much tension. He just bumbles through—it doesn’t stop him.

He’s mad on Minecraft. He really the loves outdoors as well. He’s really into animals and plants. He has pet snakes, guinea pigs, chickens, birds, and a bit of a native nursery and potted plants. We can travel and go camping. We are learning so much and have a strong connection with each other.

I would have found more benefit from not feeling the pressure that you have to do something about this NOW because if you don’t do it now all these bad things are going to happen to your kid. That was the idea of Lidcombe—you have to get it in this little window. It was so much pressure and I felt like such a failure. I was trying so hard, but I wasn’t doing the right thing by him. I wish I had had more balanced information available. With Lidcombe, you saw the statistics and it was meant to work, but nothing was changing.

You can’t see how damaging a therapy can be to your child’s self-esteem. I feel thankful that our son has bounced back from it. He’s still talking. He never cared about the way he spoke, he still doesn’t. If it gets to a point where he ever is, then maybe I’ll look at different therapies.

I found your group and book so helpful and got me to where I could let it all go. I didn’t have any others around me, I was really alone. To have that—it’s so good that it’s out there. In the

book and group they encourage you to just enjoy spending time with your kid. That's so much more beneficial. Listen to their stories, go do things with them."

