



Transcript of episode 77:

The Battle for Dyslexia Services

Emily Kircher-Morris: Hey everyone. Welcome to episode 77. I'm Emily Kircher-Morris. Micki Boas is our guest today and she'll be sharing about her experience advocating for her dyslexic child in a school system that often isn't prepared to support neurodivergent kids.

But before we get to our interview, I want to welcome our new listeners and say we are so glad that you have found us. Our listenership is increasing daily, and we rely on all of you to help us continue to grow. A few quick favors that would help us out a ton. Leave us a rating and review on your favorite podcast platform. Follow us on social media. Or support us by donating through our Patreon page. You can find links to all of our social media platforms and Patreon page on our website, neurodiversitypodcast.com. Up next.

Micki Boas: Hi, I'm Micki Boas. I'm an entrepreneur and strategist who believes in positive defiance and breaking rules and systems that don't work for us.

Emily Kircher-Morris: Stay right there.

(break)

Today we are chatting with Micki Boas, who wrote a book called *One in Five: How We're Fighting For Our Dyslexic Kids in a System That's Failing Them*. Before we get started, Micki, tell us a little bit about you and what you call positive defiance, and tell us what's in the book.

Micki Boas: So while I've done this for the likes of Nike, Samsung and other big brands, I never knew that my biggest mission of positive defiance would be taking on the education system for my two kids who learn differently. I'm a mom of two boys, uh, 11 and 8, who both have dyslexia and ADHD. And as someone who fixes problems for a living, I wanted to see how I could fix this broken education system for my kids. And in the book I talk about my story: Four years, four lawyers, and four school systems to get my kids the education that they deserved. I interviewed 200 women across the country to show that this is not a Jersey City problem, this is a national crisis that we need to address. And then in the back part of the book, I talk about solutions on how we can fix it because we don't need grandkids that are also coming against these same solutions.

So thanks for having me, Emily.

Emily Kircher-Morris: I think one of the things that really resonated in your book was that you talk about just kind of some of the mixed emotions that you had when you even first

realized that your son was going to need some extra support, um, and whether or not that would mean that he would have something official on his record.

Can you talk just a little bit about your thoughts and feelings you had in those early days of recognizing that he learned differently?

Micki Boas: Yes. I hear you talk a lot about this on your show so I'm glad you asked that question. Um, I was in denial despite so many things that were obvious. For example, my mom is a speech therapist, my husband is dyslexic and saw the early signs, and I think the societal pressures that we have as parents to have our children have this certain standard and be neurotypical, um, is what allowed me to be in denial for so long, and because of the typical ranges that our pediatricians love to tell us about.

But despite the fact that the average pediatrician visit is 10 minutes. So how are they going to really understand the depths of my children's learning abilities? And so that's what kept me in denial. And I write about in the book that staying in denial kept the bubble around me, and I wasn't quite ready mentally or physically to take on what was ahead of me, but it wasn't until he was called the 'Statue of Liberty' in class that I realized this was a major problem that I had to take on and there was no choices, and I just mustered the strength to, to fight the system and so...

Emily Kircher-Morris: You want to think that the system's going to work and you want to think that your kid's going to be just fine. It's interesting, I think, you know, when I work with my clients, I'm a mental health counselor, but I came from the field of education, and so I kind of pull from a lot of those places, and I know that there are so many parents who are so afraid of being labeled "that parent." They don't want to be the one who is, you know, rocking the boat or making people upset, or they're afraid that their child will be retaliated against in the school.

But ultimately as parents, we have that obligation to our children, you know, and, and also really, I think maybe in even a broader sense, societally. How did you get to the point where you felt comfortable in that role of being that parent, that disruptor in the school system?

Micki Boas: So I was okay with that role of being the disruptor when I realized that staying quiet was not going to get my child the results that he needed. Staying quiet is what our society teaches you so that you don't become "that parent." But it actually wasn't until 20% of the population has a learning disability. So that is one in five people on your street. And it wasn't until I started having those open and honest conversations that I realized that I was going to have to be the disruptor.

And I love this term that my publisher came up with, but I, I found so much support online and in the Facebook groups and all of these places, I found more information there than I ever did in a doctor's office. And so the disruptors really live in those groups and I accurately named them the Dyslexia Fight Club. I even made a t-shirt around it. Because we have to own it and we have to go in there and all of these span groups and these special education groups, they are playing too soft of a narrative to really get the attention, to change the

system. So that's what I'm good at in my professional life is causing a fuss, and so I tried to do that here, and that's the only way that changes happens. If we use our voices collectively.

Emily Kircher-Morris: There are so many kids who, who fall through the cracks. One of the things, when we talk about kids who have learning disabilities, learning differences, need more support. We wait for them to fail before we even offer that. And it's interesting, you mentioned like the pediatricians in those developmental milestones and it's, you're right. It's like they kind of take this wait and see approach when really we need to be much more proactive.

Micki Boas: There's three points that I make in the book and you just hit on the, one of the biggest ones, but I really talk about this trickle down effect from underfunding to early intervention to teacher training. I think those are the three systemic issues that we're facing as we try to educate dyslexic kids. Right? And so at early intervention, you can accurately diagnose a dyslexic child, as you know, at five, the typical reader should be reading by seven, but yet we diagnose two thirds of dyslexia at age 10 when it's almost too late to remediate. I mean, you know, Nadine Gaab is doing some of the most fantastic work on early intervention. And, um, we just don't screen in kindergarten and do the things that we need to do because the funding isn't there. And so, especially in this world of COVID that we're living in, uh, free and appropriate public education - it is you're right. And so, um, I'm really scared about what's going to happen as we start to deal with the effects of this pandemic, but, um, if we're not getting them screened, we don't have a shot. And so I would encourage every parent listening to your, your podcast to ask for that evaluation now, because it took me 18 months to get the support I needed for my little guy the second time around. So imagine if you are a newbie to this, it's a such an intimidating thing. And all it is is a three-sentence email. I would like my child to be evaluated.

Emily Kircher-Morris: What you were just talking about, especially with the pandemic, I think is really important. I was just talking to a parent yesterday, actually, who started the referral process for their child last February, right before the pandemic, and then everything got pushed off. And then now they're in this position and it's a year later and they still really don't have any, anything in place. And all of a sudden, again, they're really seeing the struggles that are taking place and losing all of this time.

And I think that's such an important piece. Do you feel like for, for your sons, with all of the work that you've done, have you caught up on the time that you felt like you lost initially?

Micki Boas: In terms of catching up, I think we're all facing this Covid slide, which is very similar to the summer slide, but has gone on much longer than a summer. And so the system in general was already struggling. So for example, my district in Jersey City was \$155 million under funded, so they don't have enough money to open up the school. So how are we going to catch up to your point? And I've seen some innovative solutions that people have been talking about. I'm not sure if you saw the piece from Robert Slavin on the Tutor Marshaling Plan, but he proposed an open letter to Biden to hire 300,000 tutors to close the gap. I'm seeing people submitting private bills. So potentially your practice can fill in there where they're submitting them to the district, because they're just not enough people to close that gap.

And so I've been lucky enough that my older son is in a private school and they've been on technology and have trained teachers. And so they are able to scale that. Right? My younger son on the other hand was put in a more compromising position, but they actually just went to a very interesting model where they stopped the day at one o'clock and they're providing more direct and targeted services from one to three o'clock.

So I think that there's ways it is definitely on the parents. We are definitely spending money that we do not have to find the resources that we need, and it shouldn't be that way, but I'm hoping between, you know, downloading online, you know, structured literacy curriculum and doing it yourself, watching YouTube videos, I mean, it's not ideal, but hopefully it gets us closer to closing that gap.

Emily Kircher-Morris: You had your mother who, who kind of helped you navigate that system. She helped you know to ask for the assessment and she helped you know what language to use when you're asking for those, you know, assessments or services, because there's almost this code switching that parents have to do to access those services. What are some of the lessons that you learned along the way in that area?

Micki Boas: I think as mothers, we have an instinct when something is not how it should be or is not following a normal path, and I think we keep that inside of us for too long. And so what I wish I would have known and learned along the way is to have those more open and honest conversations.

Like, my husband has dyslexia. I never knew it was genetic. Um, my son isn't walking the right way and having fine motor skills, and not the right way, he's walking differently, right? And so, um, while we see those very horribly-designed posters in our pediatrician's office about early intervention, um, I guess I wish I would have had those conversations with my neighbors earlier to understand, and it wasn't even until my mom, we were at the very, um, he was two and a half when he went into early intervention. So we were, I didn't even know about it even with the advantage of my mom. So imagine children, African-American children are five times less likely to understand and be in these programs. And so how do we get the word out to everyone? Like, why isn't this a CDC campaign? Why isn't this a, a national health crisis that we're talking about?

Because the results are fantastic when your brain is developing to get that intervention. So I would make a call it a pediatricians to have those conversations. We're not going to Sue you. They're all scared of malpractice. Right? We just want to have an open and honest conversation, and I think until we can find that middle ground of pediatricians feeling comfortable talking to us and parents not feeling like they're gas lit, I feel like that's when we're really going to be able to, to move the needle forward on early intervention.

Emily Kircher-Morris: I feel like that's also happening in the schools. I feel like teachers are afraid to make those statements too when they start seeing concerns.

Micki Boas: I think that this is a moment when technology becomes really empowering. So there's an app that I research in my book called Baby Noggin. The CDC has a milestone tracker, so you can self-track and when you bring that data to your pediatrician, data speaks

volumes, right? And so data doesn't have emotions. Data is not subjective. It's quantitative results not from a... crazy mom, which they call us all the time, right? Crazy is doing something over and over again and not being heard, right? And so if you walk in with a CDC app to your 10 minute pediatricians and you say, look, he's missing all of these milestones. Oh, he's in range. He's on the developmental curve. No, I want to have open and honest conversation.

And then to your point about teachers, there was a Seek Connecticut study that showed that 65% of teachers interviewed felt that they would receive retaliation if they spoke openly and honestly to the child. And so, I know for a fact in my four legal battles, with both schools, by the way, the teachers knew what was wrong and I could see it in their eyes. There's no money to serve them and that's why they're not speaking up. But if you approach the school that... I know there's something wrong, I want an evaluation. I will work with you. The cost of teaching four teachers the right way is the same cost as defending one lawsuit. So imagine how many teachers, four train teachers versus the retaliation of not speaking up.

Emily Kircher-Morris: In your experience, you had this opportunity to work through a variety of different types of school systems, private, charter, public, Montessori was one. Talk a little bit about what you learned that maybe were unexpected things that you didn't anticipate about the differences between those different settings.

Micki Boas: You're actually the only person that's ever asked me about that in this book interview process. So cool. Thank you. Um, I was a child and product of Montessori, and I always thought that creative learning and no boundaries was this amazing thing. And while that might work for some children, as you know, children who have learning disabilities thrive on rules and regulations and patterns. And so I think that was the number one thing that kept me in denial is that they mix the grades and they mix the spaces, so of course he was always within range.

But the biggest shocker to me was that private schools don't get any limited support to serve children with learning disabilities. And, um, while private schools recruit like like-minded cohorts, they never consider the 20% of children who learn differently. So there's very few dollars for evaluations, there's very few dollars for support, and parents end up paying a private school tuition on top of remediation services, which to me, that was the shock of, of Montessori.

Um, the charter schools in our neighborhood, um, seemed to also have like a progressive minded thinking, which I was interested in, but they get almost one third of the funding that public schools get. And, for a charter school that was supposed to be so transparent and respectful, they came up with every excuse in the book of why they couldn't give my child the services he needed.

And as we talked about data, I had neuro-psych reports, I had psychology reports, I had everything, but because I gave him, this is another big learning, because I gave him the help he needed, I wasn't allowing him to lock himself in the room and fall behind, I didn't win. I did not get the support that my child needed. And my lawyer messed up so bad, I had no idea that the public schools want nothing to do with the charter schools. So they wouldn't

show up at my meetings, they wouldn't listen, and I didn't know what options the public schools had for me.

Had I known about this earlier, I probably would have gone straight to the public schools. They have the most resources, they were super kind to me. They have a structured literacy program. They have a professional development budget. And so I'm not telling parents which way they need to go. My child is in a school for kids with learning disabilities because that is the only place that teachers are trained in my mind for his type of learning disability.

And so if I had it all to do again, um, I would probably just go straight to the special school that can help my child learn the right way the first time.

Emily Kircher-Morris: And it's interesting, there's so much inequity, just even within those, those broad categories.

Micki Boas: But listen, Emily, I talked to, this is one of my favorite interviews. I went out to Staten Island to interview Tim Costanza, who runs the first dyslexic charter school in New York City. Charter schools have flexibility and freedom, and he is training first and second graders, and he has an Orton Fellow, and all of these amazing things. So it can be done. You just have to have people like Tim and people like you and other people who are willing to fight the fight, be on the front line.

So we are definitely facing inequality when it comes to income, race, gender, evaluations, all of these types of things, but it's, it's possible.

Emily Kircher-Morris: You know, you've mentioned a couple times, Orton-Gillingham. Talk a little bit about that maybe for, for families who aren't familiar with what that means and how it has benefited your sons.

Micki Boas: Orton-Gillingham, I know we're not supposed to promote like any system, but it's the only one I can talk about, it saved my kids' lives. Um, if I could go back and do my career again, I would get trained in it myself. I don't have the patience for that, but basically it's a structured literacy program that uses the science of reading techniques to meet the child where they are at.

And so my kids have really high skills in some areas and so it takes those skills into consideration and it uses the frequency that's needed to bring them up to speed. And I spoke with the Institute for Multisensory Learning and they can get kids up to reading level in six weeks, if it's done the right way. And it costs almost like \$14 a kid to bring that into the school system. So to your point, there's ways to do it, and Orton-Gillingham is one of them, but any structured literacy program that's based in the science of reading is, is a sure fit.

Emily Kircher-Morris: There are a lot of programs that are Orton-Gillingham-based, that people don't even realize. Like, I know there's like the Wilson reading system and Spire are two that come to mind. It's all kind of under this umbrella of using the Orton-Gillingham methodology. It is strange though, isn't it? That we're not just doing this for all kids from the beginning.

Micki Boas: I mean, the research shows that, you know this, I'm sure your audience does, but everybody learns great this way and schools in Arkansas, schools in Mississippi, they've all taken on this system and the results are fantastic. I mean, it just, but why aren't we doing it, Emily? Why do you think we're not doing it?

Emily Kircher-Morris: Money. And, and lack of education and lack of understanding. I actually started teaching in, in gifted ed. That was kind of where I started my career path. It's interesting seeing, especially those kids who are very bright, who are also dyslexic and can't get those, those services, but there is such a huge divide between the general education classroom teachers and the special education classroom teachers and the gifted ed teachers.

You know, there's not this, this understanding of what's going on and all... Well, That's a broad statement, but you know, what I'm saying. It's like, especially, I think that teachers who are just in the general education classroom, they don't even always know what's going on in those special education classrooms. And that's a disservice to the students. Like you need to be able to have that bigger understanding of what's happening, I think.

Micki Boas: And that comes from Emily Hanford's work, which we all know is that four out of ten teacher training programs don't teach the science of reading. And so a special education teacher comes into the classroom having to know how to teach 13 different types of disabilities. Right? And so, whatever your thoughts are on inclusion, et cetera, to teach my kids you need another 200 hours in the science of reading, and we don't have the professional budgets to do that. So the teachers who come out of the colleges that have the science of reading are able to kind of hit the ground running.

And those who have overhauled their system like Mississippi, they went from the bottom of the NAPE scores, excuse me, up to the top. To your point, if everyone learns the best that way, why aren't we teaching all of our teachers that?

Emily Kircher-Morris: Right. Kind of shifting gears a little bit, you mentioned at the very beginning that your, your sons are dyslexic and have also have ADHD. And originally though, as you went through this process, you knew about the reading stuff and then those executive functioning difficulties came up later. How did that impact what you did, how you helped your son, how you advocated at the school, how you felt about the process?

Micki Boas: I tell my friends who have that, you know, kind of water cooler conversation: "I think there's something my kid might be dyslexic, but he doesn't flip his B's and D's," I'm like, oh, girlfriend, hold on. It is a big picture, and there's all these things, and I was lucky enough in my evaluation that my lawyer and the neuro-psych made a big point about the executive functioning, like, put on your shoes, pick up your backpack, get out the door. And so we have manipulated... since we got that diagnosis, we manipulated our life to be compartmentalized and to be organized. And it's very difficult for two parents who also have ADHD and struggled to organize themselves. So putting those systems in place was super important, and little did we know that 18 months later we would find out that my younger kid was struggling. And so putting those in place, I think helped our whole family.

And I think also in this moment of Covid asking children with ADHD to sit in front of a computer for eight hours is insane. And so how are we making accommodations for people who have such amazing skills and strengths? You know, 33% of people with dyslexia are entrepreneurs, which means they forge their own way. They've figured it out on their own. And so I'm excited to see new learning models that, that do that.

Emily Kircher-Morris: I'm wondering, as you've had conversations with your sons, how do you talk about being neurodivergent and how their brains work differently?

Micki Boas: It's a really interesting question and, um, it actually came up a lot in with the women I interviewed as well, is that I've told them from an early age that their brain just works differently. And the fact that their father is such a passionate, you know, entrepreneur, who's such a sweet and giving man, they talk about how my brain works like poppies and once they see that and they understand that in, in the context, they, they see it as a strength. Um, there's a woman I interviewed in North Carolina whose child was devastated, and then when they found out the dad had it and he had it, he was like, Oh great! I'm going to be a successful business man like my dad!

And so I think there's this, um, positive association, but let me tell you, every day we are fighting to read, every day it is a struggle, and so they're starting to see the other side of it, especially my little one, and he sees his brother thriving. Um, and so I guess that's the, the motivation they have and technology is, is a real tool, and I think I'm so glad they have that,, it wasn't there when we were growing up. I was gifted and I had those same struggles. And so, yeah, I'm, I'm, I'm, I think that can help them and encourage them.

Emily Kircher-Morris: Yeah. Well, final thoughts as we kind of wrap up.

Micki Boas: Sure.

Emily Kircher-Morris: If you're talking to another parent who's maybe just beginning to travel this path or maybe is just exhausted from the path that they've been on for awhile, what do you say to them? What advice do you give?

Micki Boas: Go to groups of people who've been there before, because they're going to show you the shortcuts and the path on how to get there. Like I said, I learned more from the dyslexia advocate group than I learned from any other professional resource. Talk to an advocate.

If you're on that other side, um, I find they're super helpful and they're super accessible in this moment. Tele-health is sometimes an option. If you want to get some tests or some pediatricians. Um, buy my book, it paints a path of what you should do, *One in Five, How We're Fighting For Our Dyslexic Kids in a System That's Failing Them*.

And if you're questioning whether something's going on with your kids, some, some tasks I've said lately is like play hide and seek in the house. Have them write you a note of where it is, look at how they're writing, you know, um, can they hear you when they're hiding? Right? How long do they hide for? There's just so many things you can tell from simple things.

And these learning disabilities are sitting at our kitchen table. So look over your shoulder on a zoom call, right? Talk to your neighbors about where your kids are reading at. And, um, like I said, trust your motherly instinct. When you know, something's up, there is, and don't be in denial like I was, and listened to smart people like Emily and get the diagnosis early and get on your way.

Emily Kircher-Morris: Micki, thank you so much for your time today.

Micki Boas: Yeah, thank you so much for having me.

Emily Kircher-Morris: Advocating for neurodivergent kids is difficult when the system is unfamiliar and complicated. Dyslexia and similar disabilities can be tricky because many dyslexic kids are bright and able to compensate for their difficulty with reading. So the fact that they need help goes unnoticed.

When I worked as a school counselor and teacher, everyone I worked with wanted to provide the very best education for every student. And we were often frustrated and bound by policies and standards that didn't make sense. I saw parents who were confused by the educational jargon, and they often felt helpless when the school couldn't offer the assistance their child needed. One obvious takeaway from this conversation with Micki is that parents need to be unafraid of rocking the boat and asking for help.

Maybe less obvious is that this applies to teachers too. As we learn more about the needs of neurodivergent kids and how many of their needs go unnoticed and unmet, we are in the position as educators to make the change happen from the inside. Whether it's tweaking the response to intervention plan within your building, pushing for policy change within your district, or advocating at the state level for more funding for our neurodiverse schools, together, we can create change that benefits all our students.

I'm Emily Kircher-Morris. I'll see you next time on the Neurodiversity Podcast.

Dave Morris: Heads up, you can find links to One in Five by Micki Boas, along with a link to the Tutoring Marshall plan Emily and Micki talked about on the episode 77 page of neurodiversitypodcast.com. Thanks to our Patreon patrons who financially support our efforts. It would be hard to imagine making it without your help. If you'd like to join them, go to patreon.com/neurodiversity. For Emily, this is Dave Morris, Emily's audio engineer and wine steward, and this podcast's executive producer. Stay safe, stay healthy. See you next time.

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