



Episode #235

**Educational Advocate Micki Boas on
Advocating for Dyslexic Students**

November 17, 2020

Debbie: Hello, Micki, welcome to the podcast.

Micki: Hi.

Debbie: I'm really excited to have this conversation today with you to talk about what I think is pretty unusual and new addition to the books for parents raising differently wired kids, you have such a cool approach to what you share. And I loved your book, it's called *One in Five: How We're Fighting For Our Dyslexic Kids in a System That's Failing Them*, which again, great title, I very much feel like the system is failing all of our differently wired kids. And, you know, before we get into why you wrote this book, and what you're hoping it does in the world, can you just take a few minutes to introduce yourself? And maybe tell us a little bit about your personal story?

Micki: Yeah, sure. Thanks so much for having me. I'm so I was brought to this story, because I'm a marketer for a living and I'm used to kind of fighting and solving problems for mission driven clients. And it wasn't until I noticed my oldest son struggling, that I realized I was going to have the toughest fight of my life. So we noticed in kindergarten that he wasn't meeting the milestones that he needed. He went into first grade, and he was diagnosed with dyslexia and ADHD. And I thought that once we got that diagnosis, it would open up a red carpet of services. And as we all know, it didn't. And he was getting 30 minutes of reading a week that he needed to support his learning style. And I kept asking for more, I said, Can I have more time? No, we don't have the money. Can I have a better trained teacher? No, we don't have time to get her training. And so I did what I know how to do best. And I fought. It took me four years for lawyers and for different school formats to get him what he needed. And I was just super upset and had no idea why I was struggling and how many other parents were struggling. And so I decided to quit my job and write this book, to help other parents get results quicker and figure out what is the root cause of this national education crisis.

Debbie: It's so good. I always get so inspired when I talk to guests who create something based on their own experience or create really what you need it right at the time when you were sifting through or slogging through might be the right word, these these years of trying to figure it out. And I, you know, you got the diagnosis pretty early. Which is something so many parents listening to this are fighting just to get that, and then we often think when we get the diagnosis. Okay, cool. Now we know what to do, we can have the plan. And as you said, Where's the red carpet of services? And unfortunately, that just really isn't the case for any of us, is it?

Micki: No, I mean, and with my youngest son, I was actually living out like I was in Groundhog Day, because with my youngest son, I couldn't even get an evaluation. So I interviewed over 200 people for this book. And I would say almost half of them struggled just to get the diagnosis, because what I've discovered is our

special education system is severely underfunded. And so if you don't want to see the problem, because you don't have the means to serve it. And so that's the main struggle in parents trying to get that diagnosis.

Debbie: Yeah. And it seems to me and and I'd love to know if this is what you found in the research that dyslexia specifically is a learning disability that is especially tricky for families to navigate because of that reluctance, like I've heard that from maybe anecdotally, that that is one that a many schools are not either, I guess, equipped to identify early, or there is just such a reluctance to do so. Is that what you found as well?

Micki: Yes. And so it's really important for listeners to remember that there's a federal law that protects us all to have the rights that we deserve. And so the laws state that we are guaranteed a free and appropriate public education. But yet, the federal government has not funded what they said in the IDEA, which was they would pick up 40% of the differential. And on a good year, which they very rarely reach, they've gotten up to 15%. So that leaves the state and local governments holding the bag I live in Jersey City, which is 155 million dollars underfunded. So how are they going to want to screen for early intervention if they don't have the resources to support it?

Debbie: So really, at the end of the day, it's a financial issue. Were there other reasons as well that you think get in the way or is the bottom line really the money?

Micki: So I kind of looked at it in a like, trickle down approach. It starts with the federal government who has not fulfilled its financial obligation, and in my mind is acting like a deadbeat dad. Um, and then it trickles down to the lack of early intervention. So if you don't have the money, you don't want to screen for it. But yet, if you screen for it, you can get children up to eighth grade reading level if it's done with the intensity that it needs. But because dyslexia is an invisible learning disability, many children use different coping skills to get around it. And two thirds of children with learning disabilities are not diagnosed or given the support that they need, which causes the great consequences I talked about in the book, which 85% of the prison population cannot read. You know, 65% of fourth graders are not reading at a proficient level. And so there's a real, there's real consequences that come when children are not able to read past that third grade threshold. And then finally, the research uncovered that if you are given the diagnosis in our screens, you're placed with a special education teacher who's being asked to educate 13 different types of disabilities in a classroom. And Emily Hanford's work, which I love so much found that four out of 10 teacher training programs, pre service teachers, going into the classrooms, do not teach the science of reading and phonics. And so the teachers are severely under trained to teach children.

Debbie: Yeah, and I'll just say to having, we have a pretty global audience, as well, like, majority of our listeners are in the US, but I lived abroad in Europe. And I know there are many listeners who are saying, yes, this is, you know, what we're dealing with in our respective countries as well, the legalities might look different, but kind of across the board dyslexia is a is something that tends to get

identified much later than it than it should be or needs to be. Because isn't it? Something that can be pretty, I don't know if simple is the way to to identify, but there are some very clear markers of when a student or a child is dyslexic. Is that right?

Micki: Yes, that's correct. And thanks for bringing that up. So the number one thing I was shocked about was that dyslexia is genetic. So my husband is dyslexic, therefore, one of our children has dyslexia. And if you have one child with dyslexia, you have a 40% chance of having a sibling with dyslexia, which is why I have two children with dyslexia. And so some of the early milestone markers, it's very important that you talk with pediatricians, the average "well visit" for a pediatrician in the US is 10 minutes. So the number one thing that you need to mention is if your partner has struggled with learning difficulties in their past or something that might look like learning disabilities, and try to get that early screening with your pediatrician, and that you can accurately diagnose dyslexia at five. However, in the US, we are not diagnosing children until about 10. And so there's a big gap when you should be reading proficiently around seven until you know three years later when children are failing. And so the early signs you can look for in you know, pre K and kindergarten is a delay in talking difficulty remembering information such as letter names. In first grade to third grade, there's difficulties with sounding out that like an apple difficulty remembering common sight words, my youngest son was refusing to take off his jacket and hiding underneath the table. And when he was asked to read, executive functioning, as you know, is very common with children with dyslexia as well, not being able to follow multiple instructions, like tire shoes, get out the door, put on your backpack, these types of things. So the sooner you can kind of recognize these, I was in denial for a very long time about the struggles and I wish I was able to get in there earlier and have those open and honest conversations. And I especially think as we're in this moment of COVID, sitting next to our kids at the table and kind of having those honest conversations about what they're feeling, trying to read with them at night, having them write you a note to find something they've hidden in the house. All of these are ways that we can uncover those red flags.

Debbie: Yeah, it's so interesting that you, you mentioned COVID because, you know when things started happening in the spring and suddenly kids who may have been moving down that traditional path, and there weren't any red flags raised by the school system, and now they're home with their parents and their parents are observing them learning maybe for the first time, you know, in their early elementary school career, and they are starting to they're noticing things. And so I think this is probably a really interesting opportunity for kids to be identified when things may have been missed if they were still going to school every day.

Micki: Yes, you're right. And it's every parent's right to send a note to their teacher, to the school administrators asking for an evaluation, those things have not stopped because of the remote learning environment. And so it's really important, because of the time that it takes, it took me an average of 18 months to get my youngest son in place. And so the quicker parents can reach out now and ask for that screening, the better you'll be as we look at 180 days of school,

Debbie: I actually would like to go into your book a little bit. Because, again, I found it to be a different experience as a reader. Different for most books about parenting kids with learning disabilities or neurodifferences in that you really walk us through your legal battle. And what you went through over the past four years in such great detail. It was riveting. And it was really insightful, because you gave us a look really at the behind the scenes of every step and that I feel such a generous gift to parents who, you know, reading an article on here things to do is so different than actually walking through it with you. So can you tell us a little bit more about why you wrote it that way, and maybe a little bit more of the kinds of things that listeners could expect to understand better through your book.

Micki: Yeah. So I was super lucky to publish a book as a first time author with Simon and Schuster. And my kind of take on telling this story was from a professional point of view of being a strategist. But I saw, like you mentioned there being books in the market, from awesome experts who have PhDs, and learning disabilities and dyslexia. And then there were books on, you know, how to approach this system. But as a professional storyteller, I thought the way to move people was to tell these emotional stories, and almost showcase an outrageous highlight reel, and use that storytelling as a platform for change. And so when I wrote about my legal story, I'm really glad that you said it gave an insider's look, because when you're going through it, it is so tragic. But um, I wanted to hack this system, I wanted to provide things that people don't tell you. So you know, you might hear from a lawyer that you need to do things a certain way. But you know, as parents were so innovative, and I wanted to kind of write a, I wish I would have known this, make sure you ask for data, make sure you write a back to school letter for parents, for teachers on the first day so that they're not waiting to get your IEP. And so what I learned from the lawyers was very interesting, but I learned more in communities like this, because the real deal, telling parents the way that it is, and kind of providing a map and a guide to hack the system was my goal and putting together these 19 women who are featured in the book, and my story and looking at alternative school formats, because I just wanted to get to like how we can make this better because one in five children have dyslexia. And the system's just not built for us. And so I was trying to make my best pass at it, how can we build it together and make a change?

Debbie: Yeah, and I just appreciate that so much. I mean, I get overwhelmed, frankly, with all the stuff that you go into such great detail about in your story. And I think many parents do. I mean, in my Tilt Together Facebook community, there are tons of questions about these very things. And, and I feel like I'm the novice in many of those communities where I show up, or, uh, you know, I'm in a listserv of parents in the New York City area, who have twice exceptional kids. And I'm learning every day just from their experiences. So this is overwhelming, I think, especially for a parent who is just discovering, you know, they're just at the very beginning of this journey. And it's just hard to know, know where to turn or what to expect as it unfolds. So, I again, I just really appreciated the detail that you went into, and I'm just like, wondering, how did you I mean, it You said you talk with other experts, and you you learned from other communities, but how did

you stay the course over four years to kind of get to this level? Have detail and be able to navigate this.

Micki: Yeah. So when I dig into something, whether it's my passion on food waste, or climate change, or I just have, I can't stop until I find the answers. And so the four years that it took for my son, I just felt that I had a right as a member of this community in Jersey City to have the school system Tell me why my child didn't have the same rights to education. And each excuse they gave, provided a whole nother ream of invisible red tape is what I call it. That's my thought leadership platform that keeps wrapping around us and threatening to mummify us and keep us silent. And that's not the way to create change. And so I, I did the research because I had a deadline with my publisher, I actually did the research and interviewed everyone in six months. So that's pretty crazy. And thank goodness for a quiet space to do that. And every moment that I Unturned something or I heard an outrageous obstacle like a parent in Nebraska being told that scented markers was more multi sensory learning, or a parent being told that if she brought in a reading tutor for her child who couldn't read that, they'd have to bring in a gymnastic tutor. For a child who can do gymnastics, I mean, comparing gymnastics to sports. And so you just had to keep going and going. And one story that absolutely breaks my heart is a woman in Washington whose daughter tried to commit suicide twice, because she didn't feel that she was up to the standards. And her mom was a special education teacher and was fighting for her. And it just seemed like there were so many different angles to take. And so I wanted to do my best to make sure that each story we were telling whether it was my story about my son having to hold up his hand and being called the Statue of Liberty, because he couldn't get help, or parents that are told that they can't get help for their child for reading, because they need new football screens in the auditorium. I mean, this is not the way that education needs to be formed. And I just stuck to it until I found the answer.

Debbie: And I'm wondering, when you found the answers, like, you know, clearly, you're talking about a broken system. And that's very much what, you know, I'm trying to bring awareness as well, you know, with untitled parenting? And do you find or have you found that the teachers themselves, the people who are working with our kids are more open in that the barriers are more at the administrative level? I'm just wondering what you have discovered it there.

Micki: Yeah. So there's an study, called this seek, Connecticut survey that showed that 65% of teachers felt that they would face retaliation for speaking up about the special needs of the child, but the parent, but in my research, I found that the teachers really do want to speak up, they know there is a problem. And so to answer your question, I've seen that the resistance really exists at the administration level. And it's simply because they don't have enough money. And so I actually believe even the administrators, I believe that everyone has a good heart. And we want to do the best for our children. The resources that were mandated by federal laws just simply aren't there.

Debbie: And let's talk then about the resources. You mentioned COVID before. I know, this is stuff that I'm seeing in my parenting communities is just longer delays,

people who may be getting you know, extra services through the school or things funded through the school, those are delayed, like, how do you see what we're experiencing right now impacting kids, either who already who have ongoing services, maybe they've already been identified as being dyslexic, or for parents who are trying to determine if their child has a learning disability.

Micki: So I think what's happening now is because the class time is limited. And whatever format you're in, the ability to provide early intervention services is limited, because the interaction time is limited. So I think there's a real onus not like Parents need one more thing to do and this crazy situation that we're all in, but I think there's a solution of parents speaking up and asking for those early intervention services and to be screened right away. And also, we have a very short window for literacy. There's 12 million kids that are going into grade school in the fall, right? And so if you're not reading by the end of third grade, you're four times more likely to drop out of high school. As a parent who has a child that is in third grade right now, I'm very scared that the literacy support is not going to be there, I'm lucky that he is getting the reading services that he still needs. But there is an onus on me to try to fill in the gaps and try to make reading fun and a time when they just want to be on their electronic devices and things like that. So there's a real there, there should be a real will, because our literacy is at stake. And it just has some great consequences. So I've seen parents downloading some online curriculum that works for dyslexic children, such as like Orton Gillingham programs, Wilson reading programs. So even if you're not a teacher, you're able to kind of provide the decoding skills and things that your child might need. There's also used resources you can use. I've also seen parents requesting private services to be provided for their children. And because I was built for brick and mortar schools, it was not built for the situation that we're in, and it just simply doesn't scale. And so I've seen parents have some success in requesting private resources he provided to fill in those gaps.

Debbie: So parents who have an IEP where their IEP can't be accommodated, some are having success by going back to the school and saying, I've identified this support source. I need you to cover the bill. Yep. Yep. That's great to know.

Micki: Yeah. I mean, it's possible, right? We're gonna get pushed back, like we're talking about all the time in the book. But yeah, it's worth a shot. Because thank goodness, the rights of the IDEA have not been taken away during this. And so it's still within your legal rights to ask for those services, and hopefully, assist the school and give them ideas on where they can provide those resources. Yeah.

Debbie: Do you have any other thoughts for students who are maybe just doing full on remote or they're doing some sort of hybrid, and they're struggling to navigate this kind of new landscape of schooling, hopefully a temporary one, but what they're dealing with right now for how they can successfully move through that?

Micki: Yeah, so dyslexic children thrive on structure. So the more structure you can have for your child during the day, the better they will respond. So for example, we have schedules printed out, I created an interactive schedule for my youngest one with all the zoom links in one place. I'm talking to them about their schedule

before the day starts at lunchtime, reminding them of their schedule. So any kind of structured environment that you can put in place for dyslexic children in this virtual world is usually helpful.

Debbie: Yes, I think that's something we're all kind of realizing the more that we can give our kids visual cues, or just kind of expectation of what their day is going to look like, is for sure. What is helping our kids the most? So can you tell us about the Invisible Red Tape thought leadership platform? Can you tell us more about that? I kind of want to know what you're, it sounds like you're starting a revolution, which I love. And I kind of want to know what your big picture vision is for what you hope to do with this book? And then and then your invisible red tape platform does in the world?

Micki: Yes. So Invisible Red Tape was actually the original name of the book. And I just felt that it was a name that worked really well, because I felt like a lot of children who are wired differently, typically go unnoticed. And the red tape that we have to cut through just is so overwhelming, that I don't understand how anyone has the will to keep moving forward with it. And so my goal with this platform was how can we tell these real stories and figure out a way around them. So for example, I'm in Jersey City, I was I'm working with a group called Jersey City together, and it's a civic organization. And we were able to get an audit on the special education budget so we can start to see where the money's being spent. And therefore we can propose changes. And that's what I hope could happen with Invisible Red Tape, that we're sharing stories. We're figuring out ways around it because, Debbie, if we wait for our grandkids to have children, for this problem to be fixed, it will be too late. And so the Invisible Red Tape is basically just it's currently a site. Um, you can also visit us on Facebook and Twitter. program. But the main goal is just to share stories to try to figure out how to hack this system and make it better.

Debbie: Yeah, crowdsourcing, what has worked for people. And it's inspiring just to hear how other people have moved through this. And that sense of, we're not alone in this, because especially going through these legal battles, if we don't have close friends or family who really get it, it can be incredibly isolating.

Micki: Yeah. And I was grateful for my friends that helped me through it. And, and that's what I wanted this to be a place where you can learn insights, because they're told and impactful stories. And you can explore solutions. I mean, I think that's, that's the part of the book I'm most proud about that I think is, is making an impact. People are seeing that if you get ahead of the problem, you can provide a great range of options. For example, one of my biggest pieces of advice I give in the book is, how do we have an argument that is based on data? Or how do we present a rational conversation around data because as you know, so many of the conversations we have are emotionally charged. But my youngest son, for example, missed the cutoff for a simple evaluation by one point. And that was such a subjective reason they were giving me as to why he couldn't be evaluated. When I actually looked at the data, I was able to get an evaluation for him by having a conversation based on data. And so many times schools tell you that you cannot have what you want, because that's just how it is. And so I feel like if we

can look at the data and question, why these decisions are being made, that can potentially help as well. Mm hmm.

Debbie: And again, that's just good life skills too, right?

Micki: I feel like so many other problems we face in this world could just take some good life skills. And the special education system is just so deep and difficult that if English isn't your first language, if you are dyslexic yourself and struggle reading, you're handed a 65-page guide and being told these are your rights and, and being asked to go through that is very overwhelming.

Debbie: Yeah, I have a copy of such a packet here. I did not read it cover to cover, I will tell you that.

Micki: Oh, no. But the good news is like in terms of being optimistic, it's possible because the laws are there that protect your children. We're in a moment now where we're sitting next to our kids at the kitchen table seeing this happen. And so I think it's as simple as you know, noting it down by taking a note of what's happening in the class. I mean, you're literally sitting next to them, and you're their best advocate. So I'm not saying it's easy, but speak up, write letters, listen to some of the other stories. And I think you can find some of your own hacks to get through.

Debbie: Absolutely. And I have just one last question on these unusual circumstances. I've very much believe and hope that this landscape of school right now and the way that we are seeing all the problems because of remote learning and hybrid learning and what we had to deal with in the spring, and what many of us are working through this fall, that hopefully this is an opportunity for us to make some much overdue changes to the traditional educational model. So do you see this as an opportunity as well beyond just parents becoming more perhaps tuned in to what's going on with their kids and identifying learning disabilities? But in terms of actually changing the system at this moment in time?

Micki: Yeah, I hundred percent believe that it's possible, for example, as we're all getting ready to vote in November, right, talk to your senators and tell them to fully fund IDEA, tell them your personal stories, because it's their job to represent you. Right. I think the burden of education is being put on parents in this moment. And I think that our collective minds are going to come together and find different ways to solve these problems. And so I do think we are at a moment of real change in education. And I think it's forcing us to look at the institutional system that hasn't worked and I think parents are going to be at the forefront of changing it. So I'm really excited to see what happens.

Debbie: Me too. Me too. It sounds like a good rallying cry. Yeah. So before we say goodbye, just tell listeners again, where are the best places for them to connect with you?

Micki: Yes, so you can email me directly at micki@invisibleredtape.com. You can find out more information at the website Invisible Red Tape. You can also find a lot of

our content on Facebook at Invisible Red Tape. So yeah, hopefully check out the book One in Five on any online platform and I'm super happy that you are having these conversations about definitely wired children and for including me in it.

Debbie: Thank you so much for sharing today and congratulations on the book.

Micki: Thank you.

RESOURCES MENTIONED:

- Micki Boas' website
- Invisible Red Tape
- *One in Five: How We're Fighting for Our Dyslexic Kids in a System That's Failing Them* by Micki Boas
- FAPE / Free and Appropriate Public Education
- IDEA / Individuals with Disabilities Education Act
- SEEK CT Survey
- Orton Gillingham / Institute for Multisensory Education
- Wilson Reading System
- Emily Hanford