



Episode #151:

**Laura Lemle Shares Her
Daughter's Journey with NVLD**

April 2, 2019

Debbie: Hi Laura, welcome to the podcast.

Laura: Glad to be here.

Debbie: Well I'm happy to bring you on. I feel like it's a long overdue conversation to talk about nonverbal learning disorder and just kind of hear your story from a parent's perspective cause I know this is very personal for you. So I would really like to just start there. So can you tell us about yourself, who you are in the world and the, the work that you do. I know you have a very full life and many pieces to your work, but maybe start by telling us about your personal story with your daughter.

Laura: So my daughter was always, seemed a little different to me when she was really little. She walked within normal limits, but she was a little passive and then she went to school and she seemed a little different than the other kids. And so when she was around four I got her evaluated and when she was five she was diagnosed with nonverbal learning disability. And that began my journey of trying to figure out what this is and how to help her deal with it.

Debbie: I'm just curious, even before you got that diagnosis, had you heard of this disability? Was it on your radar or what did you think was going on?

Laura: I really had no idea. I do have a Ph.D. in clinical psychology, but I never had any specialty with learning disabilities because I'm not a neuropsychologist. And so I just observed, you know, when she started school, a lot of, she started in the jungle gym and a lot of other kids would just engage in the jungle gym and she would just watch before she engaged. And I never, I just observed that she seemed different and I had never heard of this disability until she was given the diagnosis.

Debbie: So where did you go from there? I know for, for many, you know, the listeners of this podcast, our kids are differently wired in some way. Some have formal diagnoses, some don't. But there is that moment for most of us when we realize or learn information about what's going on with our children. But oftentimes we're not given an instruction manual. Okay, here's what you do. Here's what happens next on the path. So what did that look like for you when you got that, that identification, what was your next step?

Laura: Well, the first thing I got, I should backtrack a little. She, when we got her evaluated, that was not her diagnosis. They said, I don't even remember, that she had some something with visual-spatial issues. So then I went to a neuropsychologist that was recommended by the evaluator and the neuropsychologist along with an occupational therapist and a speech and language therapist gave her the diagnosis. So she was already with professionals when she got the diagnosis. So that part was very helpful to me because I already had a group of people around. But it was, it was surprising and I didn't really ever, I never heard about it. It's not like I didn't hear about other disabilities and

disorders. So I really look to the professionals to really try to understand what it is and what she needed and if she should, what kind of school she should be in. And that was pretty alarming to me that it really wasn't in the diagnostic nomenclature. I would say that finding a school was the most problematic part besides finding help. But I did, I was fortunate enough to have help at the beginning. So the school piece I would say was the most challenging.

Debbie: And was it evident to you that she needed something different than what, she was, I'm assuming was she in kindergarten or already in school at the time you got this information?

Laura: She was in preschool.

Debbie: In preschool. Okay. But did you kind of instantly realize that okay, she's going to need something different than just the neighborhood preschool or you know, this kind of path that I thought she would be on in terms of her education?

Laura: I was open. I knew that I always like to partner with schools and I knew that she needed collaboration between the professionals working with her and a school. Exactly what she needed I didn't know because when I had applied for her initially to go to school, I told them about what she had and they didn't think it was the right school. And then after acceptances were out, she had like learned to read fluently by the age of five. So I had no idea what to expect. That was part of what was surprising or going on this journey is, was the unexpected. I didn't know enough to know. I mean, not everybody with nonverbal learning disability learns how to decode early, but it's not, it doesn't mean that she comprehended with the same degree of her capacity as her ability to decode. So I would say that I never succeeded in finding the right school for her because I don't really believe for her the right school existed or we didn't know about it.

Debbie: Okay. And how old is she now?

Laura: She's 27.

Debbie: Okay. So she's launched, she's an adult.

Laura: Yeah, she's an adult. I wouldn't say she's launched, but I can tell you she's an adult.

Debbie: Okay. So I would love if you could talk more about then educational environments and maybe we can even take a step back. And I know that you're, you know, this isn't your specific area of expertise, but do you have kind of a general definition of non, or does a definition of nonverbal learning disorder exist, you know, in a way that's easy to summarize?

Laura: Well, one of the things we're trying to do with the nonprofit that I founded is trying to get it defined. And so the NVLD project, the nonprofit I founded, supported research to come to a consensus definition. And actually we're working on, not us, but scientists are working on changing the name. So right now we're looking to say that nonverbal learning disability is a visual-spatial deficit and they often get lost in space, have trouble reading nonverbal cues. But

there is a working definition, which I don't have in front of me that is being worked on. And it was through a meeting that we sponsored that was held at Columbia this fall. And they've had two meetings with experts in the field. To give you a, I don't have it in front of me because it's still in motion, but I would say the most distinguishing feature is the visual-spatial deficit.

Debbie: And a visual-spatial deficit would be different, or maybe there is crossover between things like a dyslexia or a dysgraphia or maybe they're, they sometimes happen together, I'm assuming?

Laura: Well, I don't think it's the same as that. I mean it's, I mean, it can take the shape of many different forms. It can be reading like non, as I said, nonverbal cues. It can be nonverbal language. It can be getting actually physically lost in space. Often, you know, it can take the form, a lot of people, not everybody with, you know, who have been diagnosed with NVLD have difficulties with math, but it's different than dysgraphia and dyslexia.

Debbie: Okay.

Laura: And I would say I'm not an expert on NVLD, but they often learn how to read early. Comprehension can be different. So they don't usually, well I can't say usually, but they often don't have issues with reading, or decoding, I should say.

Debbie: Okay. Okay. So when you were thinking about school fit, I'm curious, you know, I think a lot of us feel that a school that would really be the best fit for our child doesn't exist. I, you know, I've been homeschooling my son now for six years because that seemed to me to be the best option and we were able to swing it just work wise and financially. But when you say there wasn't a, you never really found the right fit. What, what was your daughter missing or what, what would have been the right fit? What do you think would have helped her thrive in a school setting?

Laura: For her, I think it would have been great if she was in a school where she was academically challenged, but they could help her learn how to read social cues better and deal with the social piece as well as executive functioning. And we didn't find that.

Debbie: Okay.

Laura: And so she was mainstreamed, but that wasn't the right fit either. But we were totally open to special schools. But a lot of the special schools, I was told at the time, had, most of the kids had language based learning disabilities. And another special school that I looked at when she was older, I told them the diagnosis and they weren't interested.

Debbie: And so, you know, and I, I have an international audience. So I know that, you know, this, if we talk more specifically about an IEP or the IDEA, I know that for a lot of us whose kids' just social emotional learning is kind of where their challenges lay, it can be hard to get support in a school setting. Because you know, if academically they're doing okay, then it's hard to push for that kind of

support. What is the status in terms of the education system in the U.S. in how children with NVLD are supported or not supported? Are they able to get extra services and accommodations?

Laura: Well, as far as I know, and again, this is not my area of expertise. Um, they technically, I believe, cannot get an IEP in public school because it's not a valid diagnosis in the diagnostics statistical manual. They can get services in the public setting if they have, if there are other names. There are special ed schools that do specialize with NVLD and have significant populations of students with NVLD. But in terms of the public school system, which my daughter was not part of, since it's not in the diagnostic nomenclature, technically they can't get services as far as I, as far as I know, as I said, this is not my area of expertise.

Debbie: And the DSM, just for listeners, that is the diagnostic and statistical manual of mental disorders. It's kind of the, the Bible, for lack of a better word, of mental health issues and diagnoses. And, and I, even though it is formed in the U.S. it's something that is used internationally as well. But, and this is something we've talked about when we've talked about sensory processing disorder, which is another disorder that's not formally recognized, yet we know that many kids in our community have sensory processing issues. So tell me more about, in terms of your organization, is this part of the work that you're, that you're doing is trying to get NVLD recognized as a, as a formal diagnosis?

Laura: That's our main mission.

Debbie: Okay.

Laura: To get it recognized. Because when I first founded it, I said, how can we help the most amount of people with NVLD? And I thought the best way to do that was to get it into the DSM. And so that is our main mission. And then then the question was how to do it.

Debbie: Yeah, that's what I want to know.

Laura: So that was like, okay, now that I know what I want to do, how do you do it? Cause people would often say to me, so how many people have NVLD? And I would say, I don't know. It's not a valid diagnosis. And how do you basically make something valid? People talk about invisible disabilities. This was technically a nonexistent disability. So it was, it was really challenging. And I was fortunate one day to meet a scientist who was passionate about NVLD and that's where my ideas started flowing that I really needed to support research. And fortunately I found a partner with Columbia and we've been supporting research there for many years and we're also supporting, they have experts there in the DSM, to get a group of scientists together, as I had mentioned earlier in our interview, to come up with a consensus definition. And then also we have a scientific council to help bring ideas about where do we go from here now to get it into the DSM, what do we need to demonstrate to the DSM committee that nonverbal learning disability is a separate and valid diagnosis?

- Debbie: So if it's something that isn't recognized widely, I'm just curious, you know, if parents are listening to this and they're thinking this might be what's going on with my child, is it something that in terms of the people out there who do evaluations and assessments, is it on people's radar? Is it something that really differs from, from person to person? You know, I guess I'm wondering how, how on the radar is, is this diagnosis for health professionals who are assessing students?
- Laura: You know, it's interesting you ask that question. When I first, nonprofit first launched our website, one of the most interesting things that I found was how often the diagnosis is being given all over the world. Which I had no idea because we get emails from all over the world; Australia, we've got Israel and Canada, obviously the United States, England, the Netherlands, Korea. So the diagnosis is being given. We get the same question a lot; now what? How do you treat it? What do we do, our kid is struggling. And that's been the main problem. It is being diagnosed, but parents are finding difficulty with their kids. Adults are finding difficulty often with employment. People need help. And that's one of the reasons that I started this, but I didn't know when I started this that we would be getting emails from all over the world.
- Debbie: Yeah, no, that's so interesting. And I don't know if you can answer this question, but I'm going to ask it and you tell me if you can, but is this a diagnosis, do you think, that some people give if they feel like, because from what I've read there, there is some overlap. The social, you know, the inability to kind of read social cues and those nonverbal cues is a big part of that. Which also is something that a lot of people on the autism spectrum also, that's a, that's a shared symptom. I'm just wondering in your experience, or have you read that this is a diagnosis that sometimes is given to people who don't meet the criteria for something like autism spectrum disorder, but there are clearly some nonverbal, I guess what I'm asking, is it something that people are like, well, they don't really fit into this, this, or that bucket, so it must be nonverbal learning disability?
- Laura: You're asking someone with some bias, who thinks it's a separate diagnosis, but it doesn't mean that it can't exist concurrently with somebody who has, who's on the autistic spectrum disorder. I think they can, they call them, they can be comorbid. But I can't answer how, why people are giving the diagnosis.
- Debbie: Yeah.
- Laura: I wish I could, but I don't know. I mean that's one of the, I wouldn't say it's a problem, but we don't know how some of the people who reach out to us are being diagnosed. In fact, in the future sometime we're going to put out a questionnaire on our website, which will go back to Colombia, to find out more information. We really need more information. So I would love to answer your question, but I really can't.
- Debbie: Well and it makes sense. If you're working on trying to get that that agreed upon definition that will make this work so much easier. But not knowing what criteria people are using, I can see would be challenging. So tell me this, your daughter

you said is 27 now. You first kind of entered this world when she was five. So with a lot of the people I talk with, there seems to be kind of a growing awareness and and of certain things like twice exceptionality for example. And just, kids with learning disabilities are much more quickly I think identified than they would have been 15 years ago. Are you seeing just more awareness or a willingness to support kids and students who have NVLD than when your daughter was young?

Laura: You know I think that's really a hard question for me to answer because she's graduated now. But I can tell you that, um, recently I had two people who are working for me in the organization go to the Learning Disability Association conference and they could probably answer better since I wasn't there. But I think, I think people just need to know. Like some of the special ed teachers, some knew, some didn't. So I think there still needs to be greater awareness. I think there are some special ed schools, as I said, that do specialize with nonverbal learning disability. But on a personal note, I still think there's a lot of work to be done because a lot of people haven't heard of it. And I think that teachers want to educate often, but they also need to be educated about what it is. That, I mean that is one of the reasons I did found the nonprofit.

Debbie: Yeah. I mean it seems that's where I feel like the big work has to be done. Certainly that's what I believe too and what I hear from so many parents. And I know that teachers are often so willing, you know, and they want to support their kids, but they don't even know what so many of these things look like. And therefore it's, it is an education challenge for the educators themselves.

Laura: Absolutely. And I think, I mean one of the things we want to work on as a nonprofit right now, we're not there yet, is to write a working renaming of the diagnosis since it's also a horrible name because these kids are not nonverbal. So the first thing you do is people think they're nonverbal.

Debbie: That's a good point. It, I think it initially creates a misunderstanding because you're like, no, that doesn't resonate. So.

Laura: And it's also hard to explain to people. I'm still trying to figure out a way to explain to people like you ask, cause it's not, it's not one thing. I mean I think it is a visual spatial deficit but then what is that? And then how do you describe it and then how do you make people relate to it and see how important it is?

Debbie: Right, right. Yeah, I mean, as we're talking too it is making me think of when I first dove into sensory processing disorder and one of the things I found so interesting is it can look so many different ways and I love that we're starting to just recognize all these kind of, or just be aware of all these nuances for who these kids are. Um, I think it's so important. I don't, you know, differently wired kind of encompasses this bigger definition of moving through the world in a different way. Again, maybe with a diagnosis, maybe without one. But it's more recognizing that so many of our kids have unique needs that aren't being met or they are not able to learn the way that they would best learn. And so it's exciting for me to see that there are so many different ways that we can support who these kids are and that we can look at this very, you know, this thing that, you

know, this child could be presenting normally, could be reading on time and, but there's some aspect where they're not thriving and that not able to read social cues is, is big and that affects, that will affect you throughout your whole life.

Debbie: I mentioned that we were going to be talking about this on a podcast and I heard from a lot of parents of teenagers. Because with the social challenges or struggling to read social cues, when you're a teenager, can create some big challenges because teenage life for many teens is all about social life. So I'm just wondering what that experience was like for you. Was that a particularly challenging time in your family?

Laura: Yes, it was very challenging because I would say that was, it was hard. It's lonely. And it's heart wrenching as a parent because that was the time when I would tell you that my kid really didn't have friends. And knowing that she wasn't in the right school, wanted to stay in the school and try being open to finding a different school and not finding a different school and her wanting to stay in the school. It was a very, very, very hard time. She was a very good learner. Academically she did really well. But everybody needs to be part of a community and everybody needs a peer group. So it was really hard and isolating and so she would have been better off socially in another school, if we could have found one.

Debbie: Well as as a parent, you know, I know that it's so painful to see your child not thriving. Especially I think at that age, you know, when things just are more intense and the emotions are bigger and knowing that there are parents with, with teens in that situation right now listening to this, was there anything that you did as a parent, like ways that you supported your daughter that you would, would suggest or any guidance that you have for those parents for how to support a child through that time?

Laura: Well, I think if they can find a school that's supportive and collaborative, I think if there's social situations where their kid can feel a part of. You know, I've spoken to other parents whose kids have NVLD and if there are certain commonalities that they can share with other, you know, so sometimes we were more successful in finding more of a peer group like in the summer than we were in the particular school we were at. Sometimes there's after school activities and if a child has a special interest, I've known that, and this is not something we did in particular, but I know other people have done theater. But it's really also what is particular, I also know some people like doing computer stuff and video stuff, but it's nothing, I don't really feel I am an expert at all since I don't think we were so successful. But I do think when we were finding more accepting communities for her, it was nicer.

Debbie: What kind of, you know, therapies - you mentioned occupational therapy - is that kind of the, the primary kind of support that a lot of kids with NVLD tap into? Like, what ways can we support, like formal ways, can we support these kids?

Laura: Well, you know, I think when you have one kid with NVLD, you have one kid with NVLD. I am not an expert on NVLD. I think her primary support was her neuropsychologist. I can only talk about my daughter.

Debbie: Yeah, that's fine.

Laura: You know, she had OT. She would, she had beautiful penmanship. She just never had the right pencil grip. That was the way she compensated. And you know, she dealt with the, some of the sensory issues and she worked with a speech and language therapist. She learned how to compensate academically beautifully. She loved to learn. I would always say my daughter loves to learn, now she needs to learn to live. So for us it was, when she was younger, it was mostly those three professions that gave her support and she was in some social groups. Um, to me the problem sometimes with social groups is they're not generalizable because social, the social piece is about novelty. So, but it's always good to find a community that you feel connected to. So that's what I can tell you that we did for, for our daughter. But I can't tell you that it's right for everybody.

Debbie: Right.

Laura: But that is a question that people reach out to us a lot is what can we do to help our child.

Debbie: Right.

Laura: And I think one of the things ultimately, hopefully, also will be more education for the educators besides treatment.

Debbie: So for listeners who want to learn more, um, do you have any favorite resources? Should they head over to your website and what will they find there that would be helpful for them?

Laura: We would love for people to look at our website. We have resources on our website with books. We have blogs written by experts, by people with NVLD, with parents of people with NVLD. We also have, some videos, one written by a child with NVLD when she was 12. A Columbia round table, which includes people from Columbia, this was several years ago, and a couple of outside people, including myself. And then we also have a video on what's it like to have a learning disability. So it gives somebody the ability to do something, to put themselves in the shoes of somebody with a disability. And we have a lot of information on the website. So if people want to connect, that would be a great way. And we also have times people can ask an expert a question and periodically we can answer, if we can't answer all of them. And we're really also trying to form a community because I think one of the things, at least I as a parent found, it's lonely having a child with NVLD or it's lonely having NVLD, potentially, and so it's nice to know that you're not alone.

Debbie: Yeah, absolutely. I mean, that's the primary reason why I created Tilt Parenting. But I know even, you know, within Tilt Parenting, there are smaller subgroups of parents who still feel like there's not a lot of, of connection or community of people who really understand their unique situation and the challenges, uh, their kids are facing. So that's great. So listeners, I will include links to the website and the resources that we talked about today, the videos. And, um, sounds like there's

a lot of great information there, which is awesome. So that will all be on the show notes page, so you can look that up and learn more. Well, thank you so much for taking the time to tell us your story and to share this with us today. Hopefully it will be just comforting to our listeners who have kids with NVLD and they'll know that feeling of not being alone and now have a great resource to turn to. So thank you so much.

Laura: Thank you very much for having me. It was a pleasure.

RESOURCES MENTIONED:

- [The NVLD Project](#)
- [IDEA // Individuals with Disabilities Education Act](#)
- [DSM // Diagnostic and Statistical Manual](#)
- [NVLD studies at Columbia University](#)