Episode 65: NVLD & ADHD: Linda Karanzalis’ Story

Lauren Clouser:
Welcome to the LDA podcast, a series by the Learning Disabilities Association of America. Our podcast is dedicated to exploring topics of interest to educators, individuals with learning disabilities, parents, and professionals to work towards our goal of creating a more equitable world. Hi, everyone. Welcome to the LDA podcast. I'm here today with Linda Karanzalis. Linda is a board certified cognitive specialist, author, and advocate for NVLD and ADHD, and is the most recent recipient of LDA's Harrison Sylvester Award. So, Linda, thank you so much for being on today.

Linda Karanzalis:
Oh, thanks for having me. I'm excited to be on and spread awareness about NVLD because I have NVLD.

Lauren Clouser:
Yeah. We're so happy to have you.

Linda Karanzalis:
Thank you. And it was such an honor to get that award. Thank you. I started out as a special ed teacher many years ago, and I did that because I wanted to make a difference because I struggled in school, and I didn't want anybody to struggle like me. And then I got a master's in brain-based education, and I'm a board certified cognitive specialist. So I left the school eventually because I was kinda limited to what I could do, and I wanted to really make an impact. So I did a lot of research, and I started my own learning center. I think there were only 2 in the country then.

And we really did feel that need for kids who learn differently and, you know, working with lots of ADHD kids, doing social skills, parent training, which I still continue to do. And so that's how I got involved. So I'm just really wanting to make a difference, And that's what I've been able to do. Yeah.

Lauren Clouser:
Well, could you tell us a little bit about your childhood experience with nonverbal learning
disorders? What sorts of things did you struggle with in your childhood?

**Linda Karanzalis:**
I struggled with a lot of things. And the thing is when you're a kid, you don't really know why you're struggling. And sometimes you're not really aware of it until you get older with NVLD because the way you're perceiving things, you kinda think is normal. And so people think that they're understanding you, and, you know, they're really not, and you're not understanding them. So you've gone your whole life like that, like your family not knowing that you didn't understand. So that was 1 big thing. And, you know, I didn't really have any friends. I really talked a lot.

Because with NVLD, our strength is verbal. Even though it's called nonverbal, people think we don't speak, but nonverbal means nonverbal communication. Right? So which is the majority of communication. So I would talk a lot because it's kinda like navigating your way, and you're missing up to 60 to 90%, depending on the research, which is nonverbal. And so, you know, I compensated, which many do with NVLD. That's our strength. We talk. So, like, words are our world.

And so as a child, I would talk a lot and ask a lot of questions to try to understand. But then after a while, I didn't do that anymore because I could see that that really wasn't helping, and it was annoying to other people. And especially playing with other kids, I have in the book where, you know, just they're playing in the house, and I'm talking about things, talking about how my mom cooks in the kitchen and telling them that and instead of playing house with them because it's a lot of visual observation that you don't have and process with NVLD. It's a visual spatial problem. So, you know, it really affected me. And I remember one time, I said to my mom well, I went to pick tulips for my mom because she's from Holland, and we had tulips. So I thought, oh, I'm gonna make my mom happy. It was a nice spring day.

And I went, and I chopped the tops of the heads off of the tulips. And I brought them to my mom, and she was annoyed, but I didn't know it because I couldn't pick up on it. I just went by her words, very literal. And she just said, oh, well, now I'm gonna have to enjoy these tulips in these little bowls of water. You know, I like them better in the ground, but she didn't say it like that. You know, she probably had much stronger eye contact, and her tone of voice would have been telling me that she didn't like it. And, you know, there's a lot of things that people say that they really don't mean that the meaning changes with all the nonverbal communication. It's not just the words.

So the next day, I thought we were fine, and I did it again. And she got mad at me, and I was punished. And I just felt really ashamed because I didn't know what I did wrong, and she assumed that I knew. And, you know, I didn't pick up any of the nonverbal cues, but she thought that I knew, and that's what I mean. Can you imagine going your whole life and your parents and your teachers and everyone thinks it thinks that you're understanding them, and you're not? So that has a dramatic impact on your life. It's very, very difficult. It's very different from the other disorders, ADHD, definitely sounds like it.
Lauren Clouser:
So going from misunderstanding to understanding, how did it feel when you finally got a diagnosis in your early thirties?

Linda Karanzalis:
It was really, it was amazing because I just felt so validated. I felt really validated. I felt I had a notice, like, prior to them because when I was in college, I actually thought I had got tested, and I do have intelligence. You know, I have average intelligence, and in other areas, higher with NVLD in the verbal area because the nonverbal is lower. But I actually thought in college that I was intellectually disabled. And back then, it was the r word. And so I went and got this diagnosis, but, I mean, I went to get tested because I'm like, what is wrong with me? You know? Because when you get older, it gets really harder. You know, more is expected of me, especially in college.

You have to be very independent. And so they did not know when I went for the assessment what was wrong. But she did tell me, she assured me that I wasn't any of those things because I was getting good grades in college. I was on the dean's list. And that happens to a lot of kids that I still see because it's not very well known. But, you know, like she said, I'm graduating with honors. Then I went further because then when I was teaching, I had a hard time. I was a really good teacher.

Like, I got an award from the governor. But it was really hard with all the executive functioning. I mean, I had to work really hard. Like, I had to work triple hard, and I knew, I'm always one of those people I thought that I had to work hard. But then I went, and I'm like, there's something wrong. And because I started seeing my students having a lot of the same difficulties as me. And then until I found out I had ADHD because we didn't learn anything about that.

And I had a parent that was a professor, and her son had it. And so she started telling me about ADHD, and I'm like, oh, jeez. I have this. This is part of it. But there were, I saw in the kids, there were other things that were similar to me, you know, that they were literal. And that they couldn't do math. And I just started keeping notes, and then I thought there's something else going on here that's not explained by ADHD. So then when I found out, I just felt very relieved that, you know, it wasn't my fault.

I wasn't crazy. I wasn't you know, you're misperceiving a lot of things, so you're really doubting yourself. So it was very, very validating for me, and it was kinda like a, you know, tears of joy. Yeah.

Lauren Clouser:
When you were saying, you know, that you had to work twice as hard, 3 times as hard as everybody else, that is something that's really common that we hear with people with learning disabilities. So I wanted to ask, is there any sort of strategies that you use to compensate during
that time, either before or after your diagnosis?

**Linda Karanzalis:**
So what did I do? First of all, I had a lot of depression, and I had a lot of anxiety. And I really needed to be treated for that. My parents would try to get me help, but everybody we saw was just as clueless as they were. And that really got in the way, because I was severely depressed. I was highly anxious, and it was very hard to learn and function that way because you have to be mindful. You can't learn when you're stressed out and you're in that fight or flight. You have to be calm. And so a lot of my time was spent in therapy.

And the therapist, that actually did more damage to me. So in my book, I have a section on therapy, because they were using neurotypical ways. So a lot of it was emotional struggle, depression, anxiety, and I had to learn ways to deal with that, but they really couldn't help me. So I kinda had to find my own ways, and it was really hard to do that when you're misunderstood and you're misunderstanding everybody. But as I got older and then I got into teaching, I did develop strategies. Like, in my classroom, I had strategies for me. And, you know, I had everything color coded and because I had an assistant that came in. It was my 1st year.

And, she came in, and she was looking for a temp job because she moved into the area. And it was too late to get a teaching job, and she's the one that really taught me how to deal with all that. Because when I got to college, I had no idea how to study or manage my time or anything or socialize. So I guess you could say I learned by the school of hard knocks. And a lot of times with ADHD and even NVLD, we don't learn from our experience because we're not aware, especially with NVLD. We're not understanding everything, and sometimes we think we do. So we can get angry and resentful. But what I had going for me was I had a father who would break down and explain everything to me, And he would turn my negatives into positives, and, I just had a resilience where you couldn't knock me down.

I was determined to make a difference. I just had determination. And then I learned other little strategies that I would do. Like, when I was teaching, I had a hard time putting my clothes together, especially with executive functioning and being late. You know? Getting up late with ADHD is hard and all these things you have to do to organize, so I would put my outfits together, and I would take pictures of them. And then I hung them in my closet so I knew what I was gonna wear. Or I would batch cook stuff all at once. And that way, I could have my lunch for the whole week because there were times where I would, you know, I don't have I don't have the visual memory.

**Lauren Clouser:**
Well, I was gonna ask about your experience in the classroom. Based on your own experience when you were a special education teacher and then later a cognitive specialist, do you have any advice or recommendations for
Linda Karanzalis:
I do. I do. I have some of them right here. Okay. And a lot of this I learned, during when I was teaching, and I didn't know about NVLD. But, eventually, I left to make that difference that I couldn't make in a school. But as a board certified cognitive specialist combined with special ed certification and experience I did a lot of research. And that's what I did at my learning center. We didn't do strategies because strategies will only get you so far. And executive functioning is a very common word now, but we've always known about it. But I try to go to the root of the problem. But what I did when I was teaching, this will help other teachers.

So some of these kids will look like they're misbehaving, but they're really not because they're blunt and literal, and you may feel like they're challenging you, asking you a million questions because they're trying to understand. And it may appear that the kid has a behavior problem. So you have to look beyond the behavior and see the needs and try to figure out who's NVLD in your class. I mean, they pretty much know how to deal with other learning disabilities and ADHD. But if you like, in my book, I have a screening, and it's for parents, professionals, and it's for kids and adults. And a lot of, I know that there's some psychiatrists using it because, you know, you have to get the right diagnosis. I'm getting a little off track, but we can get to that. But in the classroom, like, I'll give you an example.

I had a student named Billy, and he was playing with something. And he was distracting everyone. And I was, Billy, you know, put that away. And this isn't the time you can do it later. Well, then he takes it out again, real sneaky. And, you know, he was distracting everybody. And I said, would you mind please bringing that to me? And he didn't. And he said no.

So I let it go to the end of the lesson, and, you know, I took his plaything away. And then I asked him at the end, why did you say no? He said, because you asked me. You didn't tell me. You should've said that in the first place. But he didn't see, you know, those teacher eyes. When you give that eye contact, he did not hear a stern tone of voice, nor was he picking up on my body language. And, you know, and so voice tone is a big thing, because it's the cadence. It's the rhythm.

And so you're gonna see these kids. If you start finding yourself thinking, I know I said that, but this is what I meant. Or if you're seeing kids ask you a lot of questions or if you're seeing kids that are constantly dropping things or maybe falling out of their chair or if they're late. And they could be late because if they have to go to a locker, a lot of them can't find their way to class. So you have to really take them around and look at their schedule, especially when you have different teachers and you have to practice. Because they don't know where their body is in space, and they don't know, they don't have the visual spatial component or the visual memory or the visual discrimination. So a lot of things could look alike. So, I ended with if a flower doesn't grow, you don't fix the flower.

Right? You change the environment in which it grows, so, you know, sun, soil, all that. And that's what you kinda have to do. And you do that with a lot of kids in special ed, but, it's just doing
different things for kids with additional different things, what you would do normally, and then other things. You know? So it's really understanding. It's you know, like I said, and using the verbal. Basically, all these modifications that you need for them to be successful.

**Lauren Clouser:**
Well, Linda, I just have one more question for you before I let you go. What is one thing that you wish more people knew about NVLD?

**Linda Karanzalis:**
Well, I wrote the book because what I wanted people to know is that they're validated. It's the book that I wish that I had and that I didn't have. And then it's not your fault. Like I said, that's very validating, and that's the first step I wanted to take. What I wanted people to know is that I couldn't reach everybody. So I wanted to have more of a mass impact because these poor souls are walking around not knowing what's wrong. And parents aren't able to help their kids because I have a lot of older kids that are very resentful. So really to educate.

So I can't help everyone. I want them to know that they're not intellectually disabled. They have average to above average intelligence. And that, you know, in the back of the book, there's a...it's a very easy read, and there's lessons in there. So I would like other people to also, neurotypicals or just anyone, understand that this is not something that they're doing on purpose, and that just because you're highly verbal we tend to judge people who are well spoken. Right? But it's so hard for others to really believe in this because it's invisible. You're not equal in all areas. There's gaps.

So you would expect somebody who's highly verbal and talks to be able to do certain things, and they're gonna struggle with it. And to also know that within NVLD, nobody fits it, the profile. You may not have social skills issues, which is what the new research says, but you may have visual spatial, executive functioning, or you might just have executive functioning and sensory. You might just have, it could be anything. There's all these different combinations. And to really put themselves in the shoes of the person and know what it's like. This is high stress and to realize the other mental health problems that come across. And my main message is look beyond the behavior and see the needs, and don't just go by the behavior.

**Lauren Clouser:**
Yeah. I think that's a great note to end on. All great points. Linda, thank you so much for being on the show and for telling us a little bit more about NVLD and ADHD. And, again, congratulations on the Harrison Sylvester Award.

**Linda Karanzalis:**
Thank you. Thank you.

**Lauren Clouser:**
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resources and support, visit ldaamerica.org.