Empowering Self-Knowledge for Neurodiverse Students: A Discussion with Caroline Weaver

The LDA Podcast, Episode 57

Lauren Clouser [00:00:06]:

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 Caroline Weaver. Caroline is a learning disability advocate and a past student in the LEARN Lab at the University of Denver. Caroline's also currently pursuing a Master's of Science in education at the University of Pennsylvania and is working on a concentration in community action and social change. So, Caroline, thank you so much for being on the show with us today.

Caroline Weaver [00:00:44]:

Yeah. Thank you so much for having me. I'm really excited.

Lauren Clouser [00:00:47]:

We're so glad to have you. So to start off, would you be able to tell us about your own personal experience in school with dyslexia and dyscalculia?

Caroline Weaver [00:00:56]:

Yeah. Absolutely. So as a kid with learning disabilities, I had kind of a really love/hate relationship with school. I really love to learn, but I was also really scared of classrooms. I had kind of this weird tension between seeing schooling as a place that had so much joy, but also as a place which had a lot of suffering.

And, really, I felt a lot of shame about my learning disabilities, and I felt really embarrassed about the need to ask help or to use my accommodations. And I worked really, really hard to hide my learning disabilities because of this. At the same time, it really felt like schools and classrooms were being organized in a way which made my disability so visible. And so it was this tension of wanting to ask for help, but not knowing how to and being scared to.

Lauren Clouser [00:01:44]:

You had mentioned that you had felt sort of a lack of support around your learning disabilities. And this feeling you turned into a passion for helping other students with LD who might be in similar situations. Can you talk about that process?

Caroline Weaver [00:01:59]:

Yeah. Absolutely. So as I mentioned, I felt really embarrassed to ask for help, but I also wasn't really given the tools or the language to ask for help and to advocate for myself until I taught myself how to. And looking back, I had teachers who were probably just not that well informed about learning disabilities. But some of the comments that they made to me and about me were really harmful because I cared so much about learning, and I really loved school, but it was hard

to be successful in school, and I just felt really misunderstood by schools and by teachers that didn't really understand either.

But I was also lucky that I had some teachers who are more sensitive, and they really did want to help. And they would say things like, let me know what you need or let me know how you learn best. But I now realize statements like this without broader effort being put into helping neurodiverse learners learn about themselves is kind of pointless.

In a lot of ways, I think that when you're being told to ask for help, you're not being given the tools to understand yourself and how you learn best. It's sort of similar to telling someone who's drowning that they just need to swim. Like, you would never just tell someone to swim and assume that they know how to, but the school system does this to neurodiverse students.

And so all of that kind of just led to feeling really anxious and really angry. I was angry at schools for not knowing or not trying to help me. I was angry that I didn't feel like I had an equal opportunity to succeed despite laws that required it. But worst of all, I think I was really angry at myself for not doing well enough. And I now have come to realize it's okay to be angry, but you don't just want to get stuck being angry. Because when you're stuck in anger, you lose parts of yourself that you really, really love.

And so I think a lot of this passion comes from not wanting other neurodiverse students to be stuck being angry and really kind of working to turn that anger into a more productive tool, which is passion.

Lauren Clouser [00:04:11]:

Well, I can't wait to talk more about your research and how we can transform these experiences for neurodiverse students. But first, I wanted to ask you a little bit more, about the importance of self advocacy and self efficiency for students. Why is that so key?

Caroline Weaver [00:03:56]:

Yeah. So I think that it's important, first of all, that students can believe that they have the ability to do well and to achieve. Because if you don't have this baseline belief that you can be successful and that you can achieve what you set your mind to, you're going to be less likely to advocate for yourself because you don't know how or don't believe that it's worth it. And so part of what I'm exploring in my master's degree is that if neurodiverse students don't hold this belief that they can be successful in school, then they'll be less likely to ask for help, which is self advocacy.

Lauren Clouser [00:05:01]:

That's a great point. So I wanted to ask, what drew you to work at the LEARN Lab?

Caroline Weaver [00:04:59]:

Yeah. So I kind of found the Learn Lab by a happy accident. So I was doing my undergrad in psychology, and was really interested in the developmental psych side, and I wanted to understand the psychology of self advocacy. But in order to do an independent study, you need a faculty to supervise it. And so my adviser connected me to Lauren, and I found the lab through her.

Lauren Clouser [00:05:31]:

Fantastic. We just had on Dr. Lauren McGrath 2 episodes ago, who did a great episode on comorbidities, and there's a lot of great work being done at the LearnLab, yours included. So we're so excited to dive into that. So how has your own but how has your own personal experience shaped how you approach creating solutions for students with LD?

Caroline Weaver [00:05:52]:

Yeah. So I think that as a student with learning disabilities, a big part of your survival in schools is to be able to identify these gaps between what you need and what you understand about how you learn and what schools can and can't provide for you. And so because of this, I learned at a really young age that the school system wasn't built to consider learners like me. And so if I wanted to do well, I had to innovate and build solutions for myself.

But that wasn't easy because while I knew that school was hard for me, I often felt misunderstood, and I placed that blame on me. And so I've done a lot of work to kind of rebuild that confidence and redirect that blame. And through that work, I started to realize that all of these things that really cause pain, with the right kind of mindset and with work, it can really be used as fuel for change.

And I really strongly believe that neurodiverse students are kind of orientated in an ideal place to see the faults in the education system, which also means that they're then positioned to be catalysts for change in the education system. And so I think creating space and tools for neurodiverse voices to be more successfully heard in spaces is vital for creating solutions to making schools more inclusive.

Lauren Clouser [00:07:11]:

Absolutely. Yes. You're definitely able to see the gaps a lot more clearly. Would you be able to tell us more about your research at the LEARN Lab, and the self advocacy processes in school?

Caroline Weaver [00:07:22]:

Yeah. So I worked more generally in the LEARN lab for about 3 years, cleaning data from testing in IEPs, and then the lab takes this data, and it lets them see trends in diagnosis. And I know that Lauren talked a lot about comorbidity. That's a huge focus of the lab. But I kind of realized as a student with learning disabilities working in the lab that a lot of the testing that I was sorting through, I didn't really understand it, despite the fact that I had taken the very same tests multiple times in my disability testing. And so within the lab, I want to shout out Eliza, who's one of the amazing PhD students who did a lot of training with me to explain what the tests were for. And without that training, I would have been totally lost. But once I understood what the testing was for, it obviously helped me clean data better, but I realized how much pressure I took off of myself once I kind of understood what my diagnosis was.

I think a small example of that could be that I was tested for my learning disabilities 3 separate times, and each time I walked away from that testing feeling so defeated because I failed every test that they put in front of me. And, of course, now that I understand why we do the testing and understand the tests, I get that that's what they're designed for. They're made to push you to your limit to see where you get your answers wrong, and that's what lets you know what your learning disabilities are. But no one tells kids this, so they just walk away feeling really defeated because they just did 6 hours of testing and weren't successful on most of them. And so it was by kind of taking my understanding that the lab showed me and my personal understanding,

that I sort of started to wonder If the lack of self understanding and a more formal lack of context of disabilities could be a big barrier in self advocacy in schools.

Lauren Clouser [00:09:23]:

Definitely. Well, and I'd love to talk a little bit more about those barriers. So from your research and your experience, what are some of the main barriers that you found to implementing research based strategies in classrooms?

Caroline Weaver [00:09:37]:

Yeah. So I think the biggest one is kind of an overall lack of context, that really we're not giving the language and the tools to the kids that need it. You know, we're applying these research based strategies, but we're not explaining the research to the kids. They don't understand why this might help them be successful or why they might be feeling that way. And so I think that increasing context and accessibility to that context is really, really important. And then I think kind of under that, without that context, there's a really big lack of self knowledge and a lack of self love. You know, if students don't feel like their learning matters or that their voice can make a difference in how they learn, they're not going to speak up, and that's not their fault. It's A wider system fault of not giving access to the type of research that could make a difference.

Lauren Clouser [00:10:30]:

Definitely. So, through your research, were you able to identify any practical tools or strategies that could reduce some of this harm that neurodiverse learners often experience in classrooms?

Caroline Weaver [00:10:43]:

Yeah. So I absolutely think that providing context is, like, my number one biggest takeaway. I think that if you can increase context and understanding of how learning disabilities affect neurodiverse learners as well as providing context to why the structure of the US education system might not consider them, it can really increase self efficacy and improve self esteem, and those together kind of help foster self love.

You know, I don't think it's any one person's fault that harm is happening for neurodiverse learners, but it's most certainly not the fault of those students themselves. Though those students kind of shoulder that blame, and that doesn't help with self efficacy or self advocacy. And then another thing that I think is really important is creating pathways to see vulnerability as strength. I think at least from my experience, I worked so hard to hide my identity, and I paid a lot of the harm that I experienced in classrooms because of it.

And so I think by seeing vulnerability as a strength and as sort of a tool for creating change and healing, a lot of that process can kind of be worked around. And then, I guess, in terms of more formal tools, that's what I'm really hoping that my capstone website can help produce. I'm kind of building it to be a toolbox in and of itself.

And so, within the website, I'm kind of creating what I'm calling the radical little dictionary, and it takes the terms like comorbidities and accessibility and learning disabilities, and it really breaks those terms down into accessible the language so that if a student reads it, they're not just reading comorbidities. They're understanding what that means. And once they understand it, it gives them the language to use that tool down the line. And then another thing that I think is super important is, you know, even though I'm at Penn and I'm doing a master's thesis, I'm really writing for students and writing with accessible language in mind.

I think that a lot of times, academics kind of solely speak to the academic community, and that's okay. And there's definitely space for that. But I think that we're kind of lacking accessibility in those areas that are researching learning disabilities, but the students themselves don't understand that research.

Lauren Clouser [00:13:08]:

So how can we work to encourage this self knowledge in neurodiverse students? How can we sort of guide them?

Caroline Weaver [00:13:16]:

Yeah. So I think that there's kind of this missing link between self efficacy and self advocacy, and that really is context. So if we improve access and connections to all of the wonderful people in the field, you know, like Dr. McGrath, like the people that work for the LDA, like so many nonprofit organizations that already exist, improving students' access to those resources, I think, will help students feel more supported and more connected to the community, and will work less hard to hide their identity and might even feel more proud to know that there are people that care and that they're not alone in these feelings, and I think that that work needs to be done by those who work directly with neurodiverse students. They need to be working to create these spaces for students to learn about themselves, about how they learn, and have ways to understand all of the amazing research people that are already working so hard in this field.

Lauren Clouser [00:14:17]:

Definitely. So how can other neurodiverse learners use their lived experience to inspire change like you did.? If they want to become advocates, if they want to do research of their own, what advice would you have for them?

Caroline Weaver [00:14:32]:

Yeah. I think that the biggest one is to kind of trust yourself, and trust that the experiences that you've experienced are valid and that nothing happens in a vacuum, so there's a good chance that if you're feeling this way, someone else is feeling that way too, And kind of you can build community from those feelings instead of working so hard and to be ashamed of them and hide those feelings.

I think a lot of that comes from learning about yourself, learning how you learn, not being afraid to ask questions, and also a belief that change is not only possible, but it's necessary, that by standing up for yourself, you're also helping every other student that's going to come after you. And I think a lot of that is also kind of looping back to that belief in yourself. You know? I'm not sitting here believing that I have every answer, but I do think that my experiences and the knowledge that I took away from them are valid and that other people have experienced it too. And so if I'm vulnerable and I trust myself, I'm hoping that in the long term, that kind of produces change.

Lauren Clouser [00:15:38]:

Definitely, I love that answer. That was great. So, Caroline, what are your plans for the future? I know you mentioned your capstone website, which is going to be a great area for resources. What do you hope to do in the future?

Caroline Weaver [00:15:52]:

Yeah. Absolutely. So I hope to continue to work in disability studies and education advocacy, and I kind of am hoping to find a place where those 2 worlds meet that lets me work more directly with students and members of the neurodiverse community. You know, as I mentioned, this website is not a resource for me. It's a resource for everyone. And so I think getting as many voices into the website and as many people connected to it as possible only helps the community more. And then down the line I'm also considering going back and getting my master's in social work to kind of work more directly with student and disability support services, but from a kind of trauma informed care and community building perspective instead of an education research perspective.

Lauren Clouser [00:16:44]:

That sounds great, and I wish you all the luck in your future endeavors. So where can people go to learn more about your research and your work? Is there a place we can link to?

Caroline Weaver [00:16:55]:

Yeah. Absolutely. So the website is still under construction. I have another year of my degree left. It isn't live, so I can share the link with it to you, and maybe you could just put it in the details of the or something. And then listeners can bookmark it and return to it in a year from now when it's live. There is also an email in there if people want to reach out, that's dedicated to the website.

Lauren Clouser [00:17:24]:

Great. Yeah. Well, we definitely want to stay on top of that because I think it's gonna be a great resource. So, Caroline, is there anything else that maybe you wanted to add that maybe I haven't asked, for us to end on?

Caroline Weaver [00:17:35]:

Yeah. I think I just wanna extend a major thank you to you. I think that it's so wonderful to create space to highlight people's voices that are working in the field, and also to have pathways to that information that isn't just reading, and bringing in a multimedia perspective is so important in the disability studies world. So I just think it's so incredible that this is the work that you're doing.

Lauren Clouser [00:18:02]:

Thank you so much, and we're so glad to have you on the podcast.

Caroline Weaver [00:18:05]:

Yeah. Thank you for having me. It's wonderful.

Lauren Clouser [00:18:13]:

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