



Lived Experience, Advocacy, and Research: Working Together to Meet the Needs of Neurodiverse Students

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 again today with Caroline Weaver. Caroline is an LD advocate, a past research student at the LearnLab, and has received a master of science in education; in education, culture, and society with a concentration in community action and social change from the University of Pennsylvania's Graduate School of Education. Today we're going to talk about Caroline's awesome capstone project, which is a great intersection of research, lived experience, art, and advocacy. But before we get started, I want to recommend that you check out the other episode that we had Caroline on: Empowering Self Knowledge for Neurodiverse Students, a Discussion with Caroline Weaver.

Lauren Clouser:

If you haven't listened to that already, that'll be a great starting point. That'll really help to set up our discussion for today. So we highly recommend you check that out. So, Caroline, thank you so much for being here again.

Caroline Weaver:

Yeah. I'm so excited to be here. Thank you so much for having me.

Lauren Clouser:

Of course. You had mentioned your capstone project was a work in progress the last time you were on, and now it's finally completed, and we get to see it. And I'm so excited to dive into all of the awesome research and findings that are in this project. So to start it off, I just figured if you could briefly describe your capstone in your own words, before we dive in too deep.

Caroline Weaver:

Yeah. Absolutely. So I think I really started approaching this capstone and thinking about my experiences as a student with disabilities. I was a student who really loved to learn but who often struggled in school. I was a slow reader, and to be honest, I've always been pretty terrible at math, and all of that was because of my learning disabilities. But I think those challenges were often attributed to personal shortcomings. I was the kid who needed to stop making silly mistakes and to try harder instead of being understood as the kid who was trying as hard as I

possibly could. And on top of that, I didn't wanna be labeled as the kid with disabilities.

I just wanted to be a kid. I felt embarrassed to need extra support, and I was scared to ask questions about things that I didn't understand. And so I worked really, really hard to fly under the radar, and what that meant was that I put a lot of effort into making myself small in classrooms. Instead of putting that effort into building tools and skills that I needed to access that support that might have existed. And I say might have existed because, unfortunately, even when teachers kind of wanted to help, it didn't necessarily feel like they knew where to start. I didn't have adults who were really telling me what to do, and that's not what I needed. I needed people who really understood what it was like to be a neurodiverse learner and who were helping empower me to build solutions that would work best. And I think that that perspective was really missing, and that's what led me to create this project.

So I had the chance to design the capstone, through the concentration that you mentioned, the community action and social change, track in the education, culture, and society program, and it just felt like this really great opportunity to kind of name my experiences and bring them out into the open and let others learn from them, and to really give myself that allowance to take up space, not just as an academic and as a scholar, but also as a proud member and advocate for the neurodiverse community. And to do that, honestly, there was a lot of sitting with discomfort and a lot of unlearning that needed to happen, and all of that kind of led the website to where it's at now. So one thing that really stuck with me is all throughout school, I was always critiqued for writing in a tone that was too personal and told that my writer's voice was too conversational, and that approach would never hold up in academic spaces. And I now feel so strongly that that was a strength and not a weakness, and so I really tried to run with the idea that this work is going to be personal, and it should be conversational, and it will be honest.

Lauren Clouser:

Yeah. And I think we're gonna touch on that a lot more later in our conversation, which, again, I'm really excited to dive into. And I think I should mention too that the link to your capstone will be included in the show notes, and we highly encourage people to go check that out because it's a really awesome resource. So what were some of your main influences when creating this project?

Caroline Weaver:

Yeah. Absolutely. So I think one of the things that I talk about in my conceptual framework essay, which is on the website, is the idea that this project is supposed to stand as a love letter to learners who are not yet able to love themselves, which is part of why I use the "with love" signature all throughout the website. I really wanted to challenge that critique and reclaim that my voice is conversational. And so by using "with love," it's kind of a reminder that everything I'm doing, I'm doing it with love, and that's precisely why these personal little touches make this website so meaningful. And so, really, the biggest influence when I created this project was neurodiverse learners themselves. I tried to tap into some of those feelings that I had buried away. And instead of getting stuck and angry that I struggled, I really started to ask myself, what

do I wish I had back then? And the answer to that was someone who really got it, someone who could name and unpack how I was feeling and do so in a vulnerable and accessible way.

And at the same time, I also really wanted to think about the whole learning system. In college, I had professors like Dr. Dean Saeeda at the University of Denver who really took time to try to understand who I was and how I learned, and he encouraged me to think across academic boundaries that felt so set in place. And I remember thinking, wow. I wish I had met someone like him earlier in my life. He was so willing to learn and so willing to listen and so willing to support me and make me feel like my voice mattered in academic spaces. And I know that there are other people out there like Dean, people who want to learn about what it's like being a student navigating these learning systems that weren't built for them in mind. And so this project was also about inviting educators and researchers in and really letting them see this perspective that maybe would help them better recognize and support and understand neurodiverse learners. And then in terms of scholarly influences, I put a lot of work into trying to position neurodiverse learners as experts themselves.

You know, their lived experience is going to be way more accurate than any theory that you're gonna read about, and that's why you'll see me advocate and use for approaches found in anthropology, specifically autoethnography, which really gave me a way to use my own story as kind of a textual evidence all throughout the website. And beyond that, I really pulled from all across the academic world. I, of course, echoed the voices of disability scholars and researchers, people like Judy Heumann and Rosemarie Garland Thompson and even Lauren McGrath. I was really heavily influenced by people that were already in that field, and I was also influenced by people like bell hooks. I especially pull from her book *All About Love*, which really helped support the emotional backbone of this project. And because my undergrad is in psychology, I also looked to those theories like the hierarchy of human needs and the idea of belonging, which I guess is a very long winded way of saying I tried to cast a wide net. I didn't just wanna center one type of scholarship because I believe that experiences and expertise can come from so many places.

Lauren Clouser:

I agree. And I think that's one of the things that's so exciting about your project is it has this wide net and has these wide perspectives. It's just really wide reaching, and I think it's gonna reach a lot of people. I think a lot of people are gonna be able to connect with it more so than a strictly academic paper or something that falls specifically into one category. And speaking of that, would you be able to talk about, I mean, your website is gorgeous. And if you go to visit it, you can see all the art and collage that you use. And I was wondering if you could speak on that, your use of art and collage throughout this awesome project.

Caroline Weaver:

Yeah. Absolutely. Thank you for calling it gorgeous. So people who have known me for a long time know that collage has always been a medium that I've used and worked with, so it felt natural and personal to include it on the website. I think that there's something in my brain that

really loves the process of finding things that already exist and then arranging them in new ways to kind of create a different experience. And this mixed media approach is really indicative of how I work as a scholar too. I take these little bits and pieces from different fields and different topics, and I find a way to layer them together and on top of each other and draw those lines of connection. And if I think about it, that's how I was able to succeed in school.

It was working to fill those gaps of what I didn't know with pieces of knowledge that already existed. So that's just kind of how my brain works. It's in that layering of ideas and disciplines and voices that I think my work feels the most alive, and it feels the most like me. And I also think that people themselves are kind of inherently multidimensional, and learning isn't always linear, so it too is layered and interdisciplinary. And so the use of art and collage throughout this project just felt like a good opportunity to honor all of that complexity, both in who we are and in how we learn. And beyond that, I also kind of wanted to challenge the idea of what an academic resource could look like. When I think back to being a student in school, the types of resources that I had were things like a multiplication chart, and that was really helpful, but it wasn't fun or engaging, and so I didn't really give it much time. And by doing something like making collages as cover pages and integrating art throughout the website, I wanna make materials feel more inviting and accessible and continue to challenge what should and could be considered academic and scholarly.

Lauren Clouser:

Absolutely. Well, I think it does a great job of that.

Caroline Weaver:

Thank you.

Lauren Clouser:

So I want to go through almost piece by piece, sort of in order of the way that you have it on your website. So could you talk a little bit about experiencing harm in the school system and how that can impact somebody's sense of self, especially at a young age?

Caroline Weaver:

Yeah. So we know that schools are some of the first settings outside of kids' immediate households that they start to build an idea of what community can be and really kind of form a sense of who they are. And we also have research that shows that interpersonal experiences in early childhood have a very substantial impact on our thoughts and feelings and behaviors. And so when neurodiverse students have experiences in classrooms or in schools where their identities are misunderstood, it can leave a lasting impact on their sense of self. And if in that moment, it's, for lack of a better word, traumatizing, or those feelings are reinforced over and over again, it starts to build the narrative that school isn't a place where that student's identity can be celebrated. And when that pattern continues, it can lead to the development of a negative sense of self. And that low self esteem builds, and it can shape an understanding that no matter how hard you try, you're just gonna fail again. And in my conceptual framework essay,

I talk about how easy it is to dismiss the impact of this process.

So you might think, well, if a student does well on a test, doesn't that just reset things? And the truth is no because neurodiverse students are in schools during these foundational times in their development, and so it isn't always easy to shake both those internal and external messages about what they can achieve, and, ultimately, that can lead to a self understanding that's shaped through deficit thinking. And so even when students have these moments of success, the internalized harm and those deficit based messages can still linger. And if that becomes the foundation of how a student understands themselves, it shapes a sense of self that's not rooted in love or in potential, but in limitation and failure, and that's really the harm. And it's why looking critically at how we structure school environments and the interactions within them is so, so vital.

Lauren Clouser:

Definitely. Well, and then talk a little bit more about the deficit thinking, how that sort of places a blame on a student's identity as a student with a learning disability rather than a system that can't necessarily accommodate them. How is that harmful to students, and do we need to shift our perspective from maybe an individual to a systemic look?

Caroline Weaver:

Yeah. So if we start to think about deficit thinking in education, what really is at the core of it is an idea that a student's failure in school has to do with an aspect of that student's identity. And so it places the blame on that student, and it holds them responsible for the challenges that they might face. And so as a personal example, I talk about this on the website, I was told many times, oh, you just need to try harder next time. And while that might sound like encouragement on the surface, it often came from that underlying belief that I was a student who was either lazy or I didn't care. And if that's the first thought that comes to a person's head instead of wondering, well, maybe I didn't teach this concept in an accessible way or maybe I should have asked them before assuming that they didn't try, then that deficit narrative is being favored. And that should cause concern because it supports an idea that a student isn't succeeding. There must be something wrong with that student rather than something missing from the environment around them.

And so, well, yes, in my case, I was a student with learning disabilities, and I struggled in school, but that wasn't the only reason that I struggled. It was also because the school system and the way that the curriculum was being designed wasn't for learners like me in mind. And I talk about this more in-depth in one of my papers on the website called Schools as Sites of Suffering. But if we really take a minute to think about this messaging, if deficit based comments like this are happening again and again and again in a student's life and it's coming from adults and people that have authority, then the student is gonna start internalizing those comments. And over time, even if they know they tried hard, that deficit narrative will win, and it will feed into the self doubt cycle that we just talked about. And so that's why working alongside neurodiverse students and people who do support them need to shift and check our perspectives. Instead of asking what's wrong with this student, we should really be asking, well,

what's getting in their way, and what can we do differently to support them? And that's gonna make all the difference in whether students start to feel seen and supported and empowered in school settings.

Lauren Clouser:

Absolutely. Well, I was so excited to see you bring this up, because this is something that we've heard a lot when we have podcast episodes about self advocacy. Because a lot of the time, students with learning disabilities don't necessarily have their strengths or weaknesses in mind or know what they need. And you call this, when an educator asks a student with a learning disability, what do you need? You call this the what do you need dilemma because the students don't always inherently know what they do need. So could you tell us a little bit about this dilemma?

Caroline Weaver:

Yeah. So I introduced the what do you need dilemma in the website to highlight, as you said, a really common dynamic in classrooms, which is teachers looking to students to help adapt or guide their learning. And I wanna be really, really clear that the problem is not in that question itself. I think it's incredible to make space for students to voice their needs and to create those moments of self advocacy, which is the ability to continuously speak up for yourself. But here's the dilemma that answering what do you need relies on some really big assumptions. It assumes that the student has self understanding, self love, and self efficacy already in place, and it assumes knowledge regarding what types of resources could be available to them. And for many neurodiverse students, those forms of knowledge can be really hard to access, especially in environments where they've already been made to feel like they're falling short.

And the expectation that's being put on neurodiverse students to be these expert innovators, even though many of them already are, and try to solve the what do you need dilemma without first being given tools and language is just not realistic. It's setting both students and their teachers up for failure. And so in my conceptual framework essay, I talk through some of these barriers that make that question difficult to answer more in-depth. But just to name a few, it's really down to the low self esteem present in many members of the population, the harm that they're experiencing in classroom settings, the lack of accessible information to understand disability diagnosis, and the emotional toll that comes from navigating all of that. You know, we have research that shows that learning disabilities are highly comorbid with mental health concerns like anxiety and depression. And when you put all of those things together, it starts to become clear that the process advocating for equal and fair treatment is just impossible when one lacks a foundation to do so. And so I, of course, encourage educators to keep asking students what they need, but I also encourage them to take a second to really try to understand if that student has been set up to productively answer that question. And if the answer is no, then that's really where the work needs to begin.

Absolutely.

Lauren Clouser:

So I wanted to talk a little bit more about misconceptions about identity. We talked about how deficit thinking can place a blame on a student's identity, how it can impact their self worth. So your project shared that self advocacy from a lived experience is a powerful tool to correct misconceptions about identity that others might have. And you also discussed this as a way to resist harm. Could you expand a little bit about what you meant by how this is a way to resist harm?

Caroline Weaver:

Yeah. Absolutely. So I like to think about self advocacy as a tool, but also as a first step in a collaborative process. I think that encouraging self advocacy does stem from efforts put on neurodiverse students. You know? There's labor attached to working towards positive internal understandings of self and then having that courage to speak up about what you need. But if we can think about self advocacy as an expression of self love, as a way for learners to treat themselves with kindness and respect and accept who they are and how they learn, then self advocacy becomes something that's even more powerful. It becomes a necessary way to bridge that gap between lived experience and a larger call for change. And so, yes, that's starting with one individual, but when a student names what's not working, they're pointing out the ways that a system has failed them and potentially even harmed them.

And that creates this really beautiful moment for collaboration to happen, for someone with a person that has power in a school to really step in, not to fix the student, but to try to listen and build something better together. And so while advocating for yourself does come from internal effort, the step is actually calling attention to those gaps in what you need. And when you have the tools to say, this is what I want, and this is what I need, and this is what I'm not getting, you're pushing back against being harmed or overlooked or misrepresented. And that's a really powerful form of resistance, And it can make a difference not only in your educational journey, but for the students who are gonna come after you too. And I think that's just such an important topic. And if it's something that sounds interesting to any of our listeners, I really break it down accessibly n-depth in a paper called lessons never taught, self advocacy as resistance that's on the website.

Lauren Clouser:

Yeah. I really love that answer because so many of the advocates that come on the show talk about how they wanna make it easier for the next person, how they don't want the next person to go through what they went through. And that's really a great way to start to bring about that awareness and that change. So, again, I'm so glad that you brought that up. And I wanted to switch over a little bit more to the research side because that is also another part of your identity, another part of your project. So why is it important to include neurodiverse identities in research rather than just thinking of neurodiverse individuals as the product for this research?

Caroline Weaver:

Yeah. One thing you'll see all throughout the website is that I tried very, very intentionally to

make pathways to include neurodiverse identities in these conversations because at the end of the day, these conversations are about them. And so one way I approached doing that was by using accessible language and creating kind of dictionary style explanations of key topics and ideas, and that was actually inspired by another tool that I was given, which was a word bank, because I often really struggled to spell, but it pushed it even further. It tried to make those abstract and scary and hard to understand research terms more accessible and usable for students. And I think that that kind of accessibility isn't just a nice add on. It's a way to signal to learners that their voices matter and that they deserve to engage in research and ideas related to their identities. And that's really a small example of a much larger push, one that calls for actionable shifts in the way that we conduct research within our diverse communities. I think that too often, research is written for other researchers, and if we think about it, that makes sense.

Right? There's an expectation to produce hard data and to be empirical and to build a case with facts and figures, and those are really important long term goals. But at the same time, when we only speak to researchers and we don't take time and care to include those who the research is being built from, we miss this huge opportunity for research and community action to meet in that moment. Because neurodevelopmental research, it needs to be methodical, and it needs to be empirical. It's about science, but it's also about people. And I think that qualitative work is important, and we need to keep doing it, but it's not more important than the quantitative work. And I think a question that I kept asking myself was, well, what could collaborative research look like? And I wanted answers. So if you head to the reimagining research section on my website, you can find a paper where I interviewed Rochelle Johnson, who's a neurodiverse community member who's doing neurodiversity research. And I also interviewed Dr. Lauren McGrath who runs the LEARN Lab.

I know that she was also on a podcast episode, and I had the privilege of working with her for three years doing neurodevelopmental research. And through my conversations with both of these scholars, we kept coming back to the shared conclusion that by working to see neurodiverse people as cocreators in research instead of just being a product for it, the research gets so much better. We not only center community voices and experiences, but we also create more comprehensive research practices. And I think that's so important because it allows neurodiverse community members to step into these spaces, which they might not have felt like they could otherwise. And I would actually argue that they're overqualified to be stepping into these spaces. They have a perspective that a lot of other people are missing. And by making room for those voices, we're not just doing better research. We're actively dismantling barriers, and we're building meaningful pathways for researchers, practitioners, and community members to work in partnership.

Lauren Clouser:

Absolutely. And, I mean, it's just like you said earlier that individuals with learning disabilities are experts. Their lived experience makes them experts. So I think that's a really exciting conversation that you had and to just see how people are looking at things differently and in a more comprehensive way as well. And speaking of comprehension, this project stems from your

lived experience as an individual with learning disabilities and also as a researcher in the field. These identities aren't necessarily separate. In your case, they're combined. So what do you want neurodiverse individuals to take away from this capstone, and what do you want fellow professionals to take away?

Caroline Weaver:

Yeah. I think I spent a lot of time wondering if this project was gonna read as academic enough, and I sat with that feeling for a while before realizing that I've sat with that feeling my whole life. And the fear around showing up authentically and not being good enough has been following me for years. And to be honest, I don't think it's ever gonna fully go away, but it doesn't have the same power that I allowed it to have. I've come to realize, especially after sharing this project with others, that who I am and what I hope to do and how I dream towards doing it is precisely what makes this project so unique. You know? It isn't powerful despite being personal. It's powerful because it's personal. And so I let myself stop trying to sound academic enough, and instead, I really focused on making it honest enough to mean something.

And so for neurodiverse learners, I hope that they can see this project as a way to know that they're not alone in their experiences and that while it can feel scary and isolating, that there are so many people out there who have felt exactly how they're feeling and who have come out of it on the other side. And I hope it's a reminder that they need to stop trying to change themselves to fit into this tiny mold of what a successful student is supposed to look like. And instead, I hope it makes them feel empowered to widen that definition and to push others to see that learning and success can look like so many different ways if we stop trying to fit into this tiny mold and instead we break it. And I know that that's so scary to show up authentically, especially when you've tried before and it hasn't worked. And that's why it feels important to say, I'm not sitting here pretending like I have all of the answers or I've come out on the other side of this, and all my problems have magically gone away. Even during this master's program when I was building this website and where I was doing work that I loved and I felt so strongly about, I still had self doubt in days where the weight of the education system just felt way too heavy. And the truth is sometimes you can try as hard as you can, and the system is still gonna fail you. But that's exactly where we put the work in to change the system and not change ourselves.

Because when you self advocate, you're not only trying to make education better. You know? You're trying to make it better for everyone, and I'm trying too. And there are so many other people who are trying and who care so deeply about supporting learners. And that's exactly where those who work alongside neurodiverse identities, like educators, counselors, parents, researchers, friends, that's where they come in. And the truth is that no one person can magically fix an inaccessible system. So my call to action in this website and really for those who are listening is to take responsibility for the part you can play and just getting us one step closer to informed, accessible, and loving education practices. Think that working to change doesn't have to mean overhauling a whole system, but it can look like working towards making these small but really meaningful shifts in the spaces that you already belong to. And that's why I encourage you to work up on work on showing up authentically too, you know, and to remind

yourself that no one expects you to have the answers.

What matters is that you're trying to listen and you're doing so with love. And even the fact that people are listening to this and have made it this far into the episode, I think, is amazing. And if people take even fifteen minutes to look at this website, maybe they'll find a resource or reflection that makes them pause just for a minute and rethink what's possible.

Lauren Clouser:

Absolutely. And what a great note as we start to wrap up. What a great call to action too. And I just wanna mention too, as somebody who's been on the website and who is not a researcher, it's very accessible. So don't be intimidated. You know, like you said, you were worried about it being, quote, unquote, professional enough. There is this real science to practice gap in the field, and this is something that sort of bridges across those barriers, but I think it's a really great step in the right direction.

And I really wanna encourage everyone: don't be intimidated. Go check it out. And I just wanted to wrap up really quick with what are your next plans and how can people reach out to you?

Caroline Weaver:

Yeah. So I've always been really interested in how students learn. That's part of what led me to study psychology in undergrad and eventually to pursue this master's degree. But this project really solidified that my passion does lie in student support. I think that that's the place that I found I can really honor my ability to identify those gaps between what's needed and what's provided and what's understood and then position myself in a way that allows me to accessibly bridge all of that. And so I don't just wanna write and talk about accessible education. I wanna keep being part of building and supporting systems and creating tools that live up to those standards. And I think that that's exciting because there are so many ways that you can pursue that goal, whether it's disability advocacy, research, maybe even fields that I haven't thought of yet because I think that I already kind of tend to think across disciplines, and so finding those points of connection between different systems lets me support students wherever I end up.

And if this project has taught me anything, it's that sometimes those meaningful opportunities are the ones that you don't necessarily see coming, but they're the ones that you recognize as being right because they align with who you are and what you believe in. And for me, that's always gonna be centering students' needs in accessible ways. And so please, I really encourage people to reach out either through the website directly or through the email that's on it. I would really love to connect and hear your stories and talk about how your dream words change because at the end of the day, I think the most radical thing you can do in education is speak up, listen, and to make room for love because every learner has a powerful story, and it's one that can be told and received when we offer the right tools to do so.

Lauren Clouser:

Absolutely. Well, Caroline, thank you so much for being on the show yet again. I was so excited

to talk to you about this project, and thank you so much for taking the time to talk to us about it.

Caroline Weaver:

Yeah. Thank you so much for having me on. I think, as you mentioned, there is such a gap sometimes between experience and research, and that gap needs to be filled. And so I feel honored that I can kind of start to position myself in that place. And I know that there are other people that also live in that world, so it's just exciting to remind myself and to remind others that those people are out there.

Lauren Clouser:

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