

What to Expect When Your Child Has a Learning Disability, Part 2

Lauren 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. Welcome to the LDA Podcast. I'm here today with Cindy Cipoletti, she's the CEO of LDA, an attorney, and a parent of a child with LD. So Cindy, thank you so much for being here.

Cindy Cipoletti 00:33

Thank you very much for having me.

Lauren 00:35

So just to kick off, Cindy, could you give us a brief background about your story as a parent of an individual with LD?

Cindy Cipoletti 00:43

Sure. So my son Jake was initially identified as having ADHD at a very early age, probably around five. He was also identified as having Pervasive Developmental Disorder, or PDD, which we later found out was inaccurate identification and diagnosis. So he went to public school K through 12. But it really wasn't until he was in early high school that we learned he had dysgraphia, which is a learning disability that affects handwriting and motor skills. And as a lot of students with LD, he continued to struggle with ADHD, executive function, and dyspraxia, which causes difficulty with movement and coordination. So fortunately, even though he had an inaccurate diagnosis early, it prompted us to get him some support, such as occupational therapy for his movement and coordination issues and fine motor skills. You know, he had an IEP in school starting in first grade, but it became apparent very quickly that his diagnosis was not quite right. But at that time, I didn't know very much about learning disabilities. And since he was performing well academically and scoring above average on standardized tests, I never really thought he might actually be struggling with LD. You know, he was getting support in school, mostly for appropriate social interaction, which a lot of kids with ADHD struggle with. But the supports he was getting weren't helping with his dysgraphia because no one had identified that as a problem. Honestly, he had great teachers who really cared, I just don't think it was even on anyone's radar. And I see that as a shortfall in how general education teachers are taught to identify learning disabilities. It was a struggle for him all through school. And in even when, though, he continued to score well on standardized tests and assessments, by the time he was in high school, he was getting mostly B's and C's, and even that was a struggle.

Lauren 02:47

Well it was good that you were able to get an early identification, at least for the ADHD. I know that's not always the case for a lot of parents. Sometimes identification comes later or it can be inaccurate as well. So if you suspect that your child has a learning disability, what should your first steps as a parent be?

Cindy Cipoletti 03:08

Well, this would depend I guess, on how old your child is, right? When you first suspect that they might have the learning disability, the earlier child is identified and gets the appropriate intervention, then the more successful they can be, and the better they're going to be able to do in school. So if your child is already enrolled in school, and you suspect they may have a learning disability, the first step would be to request in writing an evaluation from the school. If your child has not yet enrolled in school, so maybe they're in preschool or it's before they start kindergarten, then I would tell parents to discuss your concerns with your child's pediatrician. And look into some early screening options. There are a lot of new early screening options popping up and some can even be done online now too.

Lauren 03:58

Definitely. Well, and if your child is in school, do parents have any rights when requesting an evaluation?

Cindy Cipoletti 04:06

Yeah, absolutely. So parents have the right under the Individuals with Disabilities Education Act, or IDEA, to request an evaluation of their child which the law provides should be performed within 60 days of that request. A lot of states have their own timelines. So generally, the schools will follow whatever the state mandated timeline. There's no cost. So that that's part of the law is that you are entitled to have your child evaluated for a learning disability and there is no cost to the family.

Lauren 04:42

Right. And what can parents do if they don't agree with the school's evaluation? Say either they don't think the child has the learning disability that they do have or they come back with a negative that there is no learning disability and the parents disagree. What can they do?

Cindy Cipoletti 04:57

Yeah, that's that's a really good question. Parents can request an independent educational evaluation for their child if they don't agree with what the school's evaluation says. They can request that the school pay for that individual or independent education evaluation, but you'll have to show why that's necessary and the school might disagree with you and, and, you know, decline to pay for it. But as a parent, you can always have an independent evaluation done and pay for it yourself. They can be quite pricey. But if you if you really feel that the the evaluation is wrong, or inaccurate, you can definitely take that route. The school has to consider the independent education evaluation, but it doesn't have to accept the results or recommendation. The IEE, the independent education evaluation, will become part of your child's educational record. But again, the school doesn't necessarily have to accept the results. In my case, for Jake, I had a private evaluation done before he was even evaluated by the school. So the school was good about incorporating that evaluation into his IEP as well. But I know that that's not necessarily always the case.

Lauren 06:22

Right. So what types of professionals that are either inside the school or outside, can parents turn to for help?

Cindy Cipoletti 06:30

Well, there are a lot of supports. There are a lot of supports out there for parents, professionals, and just general supports inside the school parents can turn to. Their child's teachers, support staff, school psychologists, counselors, I always recommend starting with your child's teacher because they spend the most time with your child. And this is especially true in the early elementary school years when students aren't really switching classes and they're spending most of their day with one teacher. Obviously, that changes a little bit as they get into middle school and high school and they're changing classes during the day. But I always recommend starting there. Outside of school, there's a lot of resources for parents, depending on the needs of your child, occupational therapy, speech and language therapy, psychologists, tutors. There's support organizations like LDA can that can offer help and resources for families and students. You know, there are there are millions of students with learning disabilities in this country. So you know, parents, you're not alone, we're a community who is large and can help each other a lot.

Lauren 07:45

Absolutely. So moving on from evaluations, would you be able to explain the difference between an IEP and a 504 Plan?

Cindy Cipoletti 07:54

Yes, and actually, that's a question that we get a lot. But let me talk first about the two different federal laws that actually apply here. So the Individuals with Disabilities Education Act, or IDEA, is a federal education law requiring school districts to offer a free appropriate public education, you may have heard that referred to as FAPE for students with disabilities in the least restrictive environment. So that's one law. Section 504 of the Rehabilitation Act of 1973 is a different law. That's a federal civil rights law that prohibits discrimination on the basis of disability in programs and activities that receive federal financial assistance. So those are the two different laws that we're talking about when we talk about the difference between an IEP and a 504 plan. So when we're talking about IDEA, and the IEP, if a child is determined to be eligible for special education services, under the IDEA, he or she will be offered an IEP. There are 13 disability categories under the IDEA, and a student must have one of those disabilities. And that disability must affect their educational performance in order for them to qualify for an IEP, an Individualized Education Program. The IEP lays out a program of special education instruction, so it's it's really a roadmap. It sets forth supports and related services that the child needs to make progress and thrive in school. It's a very detailed plan, it contains goals, measurable outcomes, details of modified instruction and timelines for those measurable outcomes. So that's the IEP. And again, that is, the IDEA is sort the law that that falls under. A 504 plan, which again refers to Section 504 of the Rehabilitation Act of 1973, is a different method for students with disabilities to get the supports that they need. It's sort of a blueprint for how the school can provide support and remove barriers for a student with a disability. Unlike an IEP, there's no standard 504 plan. And section 504 has a broader definition of disability than does the IDEA. So sometimes students who may not qualify under

IDEA for an IEP can actually get the support and accommodations they need through a 504 plan. And I just kind of want to offer, you know, a little bit of a story, a little anecdotal story about, you know, why this can be important. From a personal standpoint, I can say that Jake had an IEP. But when he got to high school, he kind of, like a lot of teenagers do, is like 'I don't want to be singled out anymore. I don't want to be pulled out of the classroom, I always feel different. It's, you know, I don't think that what I'm getting is really helping me.' And I agreed with him, right, because he didn't really have the right diagnosis. So by the time he got to high school, you know, there was no, there were no more social issues, you know, he was doing fine socially. So, so we decided, as a family, that we were not going to pursue him having an IEP in high school. So I met with the principal at his school and talked about, well, maybe we need to put a 504 plan in place, because he was still, you know, he still had some of those ADHD executive function issues that really affect individuals for the rest of their lives, right? And as a 14 or 15 year old, they were still interfering, really with his ability to do the best that he could in school. So I, you know, I hate say I say this, and I hate to admit it, but I allowed myself to be talked out of that. And I don't blame the principal of the school, you know, as far as it's a large school district and for the school administration, they kind of really didn't see him as being that big of a problem, or that this was even necessary. So I just sort of said, Okay, well, we'll just, we'll just manage it, we'll do what we can. And that didn't, that didn't work out well. So there was this, if he was placed in a situation where being in a study hall, in a cafeteria with 60 other kids every day, any parent out there who has a child with ADHD knows that that's a lot of stimulation. And, you know, young teenage boys don't always make the best choices anyway. So he ended up getting in some trouble, which resulted in a five day out of school suspension. And I really think had I insisted on the 504 plan, we could have made some accommodations for him to be in a different study hall, you know, a quieter area with less students. So that was, you know, a live and learn. I call it kind of a parenting fail on my part. But an important lesson, I think, for me as a parent, but also for other parents going forward is to don't let yourself be talked out of something that you know is the right choice for you and your child.

Lauren 13:24

So, back to IEPs, how should you prepare for your first IEP meetings? What are some things that you can expect?

Cindy Cipoletti 13:31

Yeah, this is a sort of another live and learn situation. If you are new to IEP, and you're about to go into your child's first IEP meeting, write down your specific concerns for your child. Because when you get into that meeting, you may think that you'll remember what you want to say, but it can be overwhelming. Even as someone who is an attorney, and I would consider myself fairly educated in this area, I was intimidated going into my first IEP meeting. And you tend to forget what you want to say. So write down your specific concerns. List challenges that your child is struggling with in school, such as learning, or focusing, or reading, keep track of subjects that they are having a hard time with, and anything else that you really want to make sure that you communicate and don't forget. I would request that the school provide you with any evaluations and proposed goals or objectives prior to the meeting. Bring a notebook, something to write with, any evaluations that you may have had done outside of the school. And be prepared for the meeting to be a little bit emotional and stressful, especially if it's your first one. It can be really difficult to discuss your child's challenges and to hear about them from other people, some of whom you may not know. So don't be surprised to go into your first or your second or your third

IEP meeting, and come out feeling a little emotional, a little stressed, or a lot emotional and a lot stressed. That's really normal. And I would also say to be prepared, and don't be afraid to ask questions or voice your opinions. It can be intimidating, you know, you feel like everybody else in the meeting knows more than you, they know the processes, they know the terminology. But don't be afraid if you don't understand something. Or if somebody uses a term that is unfamiliar to you don't feel that you can't ask what that means. Make sure you ask. That's the time to do it. Don't leave that meeting, feeling like I have no idea what just happened there. And know that you don't have to sign the IEP at that meeting. If you feel like you need some time to process it or to maybe go home, talk it over with your family, whatever you need to do. You don't you don't need to sign that IEP right there. So special education services won't start until that IEP is signed, but if you need a couple days, make sure you do that. Make sure you take that time for yourself.

Lauren 16:15

Definitely, that's huge. So who is present at the IEP meetings? Is the student present? And who can you expect to be on that team?

Cindy Cipoletti 16:24

Yeah, so there'll be a little bit of a difference state to state on this. But generally speaking, the student is always allowed to be at the meeting. So it's a parent's decision, whether they think it's beneficial for your student to be at that meeting or not. I never felt it was beneficial for Jake to be at that meeting, because I felt that he got very frustrated and a little bit ashamed when he heard people speaking about him kind of in that way. But that's not necessarily the case for all students, depending on what their issues are. So the student is always allowed to be at the meeting, a parent or guardian is required to be at the meeting, a general education teacher is required to be at the meeting. That may or may not be your child's teacher, that role may just vary depending on the school district. The special education teacher is required to be at the meeting, a representative from the school or the local education agency is required to be there, someone who can interpret evaluation results, so like a school psychologist or speech pathologist, or another special education teacher, and then anyone else that is invited by the parent or guardian is also able to be there. So if you have an advocate or a case manager or someone else that you want to be a part of that meeting to either be a support to you or you think can offer valuable input on your child, that person can be there as well.

Lauren 17:59

Do you have a recommendation for a point where a parent or caregiver might need to hire an advocate or an attorney?

Cindy Cipoletti 18:07

Yeah, you know, you hopefully, you never want to be at that point. Parents, you may choose to hire an advocate at some point, you obviously don't need to, because you as the parent or caregiver can be your child's best advocate. But if you're concerned that you're not able to effectively communicate with your child's IEP team, or you don't feel like the team is listening to you or your concerns, you might decide that an advocate would be helpful in making sure that your child's needs are met. So at this stage in the IEP meetings, you don't need to have an advocate unless you feel like maybe they would

help you communicate better. Or if you feel like nobody's listening to you, for one reason or another. And you really want somebody there to be able to communicate more effectively with the team.

Lauren 19:01

Well, you'd mentioned before in the IEP meetings that can sometimes be a little intimidating for parents, seeing as there's people who use different lingo and seem to know steps already. So what is the role of a parent or a caregiver in an IEP meeting?

Cindy Cipoletti 19:15

I would say that the parent role is the most important role in that meeting. You know your child better than anyone else. So whether you're a parent or a caregiver, or the primary caregiver of that child, you know your child better than anyone else, and you're going to be able to provide the most input on your child struggles, on their strengths, on their weaknesses, where they're succeeding, where they're failing, and how they'll respond to certain approaches. So like I said before, it's really easy to be intimidated in that process. But you know, your role as a parent or caregiver is to make sure you provide the team with all the information about your child that you think needs to be considered in the development of their IEP. And again, if the team is using words and phrases you don't understand, ask questions. That's the time. No one knows your child better than you do. So be that person to provide-I would err on the side of over communicating, just to make sure that everyone knows exactly what they need to know.

Lauren 20:26

Absolutely. So how often are IEP meetings? And when can you expect your child to get a new IEP?

Cindy Cipoletti 20:32

Well if your child already receives special education services, the school typically must reevaluate at least every three years. You can request a reevaluation more often than that, but not more than once a year generally. And the school has to have your consent to do new testing, but not necessarily to review the existing data on your child. So that's required every three years. But you can request it more often than that, and especially if you feel that your child's IEP is, after two years, you feel like they really need to have this reevaluated because the goals or whatever aren't pertinent any more, then definitely, definitely request a reevaluation.

Lauren 21:27

So how often do students need to be evaluated for a learning disability? Is that a similar timeline to an IEP? Or is that different?

Cindy Cipoletti 21:34

So if your child's already been evaluated, again, you can request a reevaluation. If you feel like there's new information or that something's changed, again, you can request that new testing is done. Like I said, the school has to have your consent to do new testing. If you feel like the IEP is ineffective because there maybe isn't a correct identification, you can do a couple of things, right? If you've had, you can get an independent education evaluation done yourself outside of the school, you can offer documentation of how the goals aren't being met, or aren't relevant or applicable to your child

anymore. There's a lot of different things you can do. The reevaluation process, if you think there's a different identification that needs to be made that's not in that IEP, then you need to have that request done as soon as possible.

Lauren 22:39

Well and for college as well, what sort of documentation for a learning disability evaluation do students currently need to have?

Cindy Cipoletti 22:48

So college is a little bit different. And this varies a little bit school to school, actually, I would say it varies a lot school to school. Right now, as it stands, there is no federal law that says that any school has to take into account a student's IEP or 504 plan from high school in evaluating what accommodations that student might need in college. A lot of schools do it anyway, they will accept those as documentation of a disability, and use those accordingly. But there's no requirement to do so. Usually, the offices of disability services within universities are helpful, and a lot of them have their own processes in place for for doing that. But that really varies school to school, there is legislation that's pending that would require higher education institutions to consider recent IEP or 504 plans as evidence of that student's disability when they enter college.

Lauren 24:07

So who should you reach out to if you feel like your child's IEP is ineffective? And what sorts of documentation should you have? Or rights should you be aware of as a parent?

Cindy Cipoletti 24:19

So the first thing you should do if you feel like your child's IEP is ineffective is request a reevaluation. Offer documentation or examples of how the goals of the IEP aren't being met or aren't relevant or aren't applicable anymore. Like I said before, you can have an independent evaluation done. Many disputes can be resolved just by talking through the disagreements or discrepancies, and I always advise parents to try to resolve any kind of disagreement amicably. Rarely is taking an adversarial approach the most effective way to resolve a dispute. However, if you aren't able to resolve things through conversations in meetings, which unfortunately happens, you do have a legal remedy under the IDEA, called due process. So due process starts when you file a written complaint against the school. After you file the complaint, you and the school will attend what's called, generally, a resolution session. And that's a meeting where both sides try to reach an agreement before going any further. And the school may agree to waive that meeting and try mediation, again, just bringing in a kind of a mediator or a third party to try and reach a resolution. We talked about maybe the need for an advocate earlier, this might be a situation where a parent should hire an attorney or an advocate if you get to this point. Under IDEA you can file a due process complaint for a dispute related to the identification, evaluation, or educational placement of a child with a disability, or the provision of a free appropriate public education. So if you feel that that's not the case for your child, then that due process is the avenue that you would take to make sure that your child's needs are being met.

Lauren 26:26

So just one last question here. This one's a little more broad, but with your personal experience, what advice would you give to parents who are new to the world of special education and learning disabilities?

Cindy Cipoletti 26:36

Well, this is one of those things where I wish I could kind of go back and give advice to my younger self. But know that there's a lot of us out there. And over the past 60 years or so, parents and advocates have paved the way for your child to succeed. There are a lot of national and local organizations out there to support you and help you navigate these waters. Our kids are amazing. They don't fit a mold. They're often seen as mischievous or difficult or challenging. But when you find what they're passionate about, and you stop trying to make them something they're not, they will amaze you with their creativity and ingenuity. You know, to quote one of my favorite films about LD, "Normal Isn't Real." So you know, there is no normal. And I would just say reach out to us at LDA if you're new to this, and we will walk the journey with you. We actually have an introductory online course coming up in the spring that will walk parents and caregivers through the process of LD identification, what all the confusing terminology means, the IEP process and the laws governing special education. So you're not in this alone. There's a lot of support out there for you and we're happy to help you in that journey.

Lauren 28:00

Absolutely. Well, Cindy, thank you so much for sharing your expertise today.

Cindy Cipoletti 28:05

Thank you for having me, and I hope that everyone out there has found this helpful in their journey.

Lauren 28:20

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