

Shining with ADHD by The Childhood Collective

Episode #215: ADHD School Advocacy: When You've Tried Everything and Nothing Is Working

Katie: Our goal today is to really show you that you do have options. Now, some of those options are going to be stressful. I'm not going to lie to you. This is a tough episode because obviously, you know, we love to hear, Yeah, I reached out to my child's teacher, and she wrote back with a list of five suggestions, and we implemented them on day one and now we're all going to get ice cream as a celebratory treat because school is going so great. But the people who this episode is for, that's not happening. And so, yeah, there are options. There are steps that you can take even when it feels really hard.

Hi there. We are The Childhood Collective, and we have helped thousands of overwhelmed parents find joy and confidence in raising their child with ADHD. I'm Katie, a speech language pathologist.

Lori: And I'm Lori.

Mallory: And I'm Mallory. And we're both child psychologists.

Lori: As busy mamas ourselves, we are on a mission to support ADHD parents on this beautiful and chaotic parenting journey.

Mallory: If you are looking for honest ADHD parenting stories, a dose of empathy with a side of humor and practical tools, you are in the right place.

Katie: Let's help your family shine with ADHD.

Lori: Welcome back to Shining with ADHD. I'm here with Katie and Mallory today, and we're diving into something that's all too common this time of year. So maybe you've been holding out hope that things at school would improve for your child, but they haven't yet. And now when you bring your concerns to the teacher or the school staff, it can feel like you're hitting a wall.

Katie: Yes. And this episode is for those of you who have already been meeting with the school. You've probably had an evaluation for your child. Maybe you even already have an IEP or a 504 plan. So that's kind of who we're talking to in this episode. And if you're at the very beginning of your school journey, that's totally fine. But this episode is going to feel like you're starting in the middle of the book. Okay. So, if you're just starting out, we actually want you to go back and listen to a few of our earlier episodes. And in those episodes, we really explain in depth the process and the very first steps, like how to ask for an evaluation, how to bring these concerns to your teacher, and even things like what are the differences between a 504 plan and IEP? So, when I say those words, if you're like, I'm already lost, you want to go back and check out a few previous episodes, and we've linked episodes 161 and 165 in the show notes to get you started.

Mallory: Yep. So, if you're still listening, you might be feeling stuck and frustrated, like you and the school are just not on the same page. This episode is for you. So maybe you are disagreeing with the level of support that your child is getting.

Lori: Yep. Or maybe you disagree with the type of evaluation they did. Maybe you disagree with the results of the evaluation. We also hear all the time from parents who are frustrated about how their child is being disciplined at school. So, a lot of, you know, parents will talk to us about just the schools really focusing on punishments and suspensions and taking away recess, and not really focusing on building those skills. So that's a common issue. So, at a meeting with the school, a lot of times they're going to give you a binder of your rights. And this comes with if you've done an evaluation or if your child's got, gets an IEP, maybe they've even gotten an evaluation and they say they don't qualify for an IEP, you're still going to get this binder called your Procedural Safeguards. Not a binder, it's a paper and it's a heavy-duty amount of information and most parents just toss it to the side, but we really want you to understand that within those procedural safeguards it really goes through the fact that you have many rights and options as a parent and you don't have to take the school's decision at face value. So, they might say that they can't do X, Y or Z. Just know that you don't have to stop there, that there are other options. If you're sitting there as a parent and you're saying, wait a second, this isn't adding up. My child's getting referred constantly because of behaviors or things like that and they're saying that they don't need anything, like that doesn't add up in my mind. You have rights as a parent and, and we're going to talk more about that.

Mallory: Yeah. And that makes me think, like you said, Lori, like sometimes the school will tell you something and parents who don't know what their rights are, they just accept that even if it doesn't sit right. And I think about this mom that I was talking to at just a community event her child didn't go to my school and she was saying, oh, I'm getting ready for my son's IEP meeting because we need to modify his IEP and pull off any of his occupational therapy supports because they don't have an occupational therapist at school. And I was like, hold up, like that's not how it works. Like they don't just change your child's IEP if the team has decided your child needs that support just because they don't have an OT at the school. But she was just fully prepared to go into that meeting and pull that service that the team has decided her child really needs because she didn't know she could push back or she didn't know that she could advocate for her child to keep those services on there and talk about other options. So, we know that when you're hitting a wall with the school, it can feel so emotional, it can feel so overwhelming and we know that you just want what's best for your child, but when you don't know what your rights are, you feel like you feel stuck in advocating for those rights and for what's best for your child.

Katie: Yeah, it is so difficult. And so, if you're at that place, you've already tried talking with them and requesting things in writing, and it just does not feel like things are working, our goal today is to really show you that you do have options. Now, some of those options are going to be stressful. I'm not going to lie to you. This is a tough episode because obviously, you know, we love to hear, yeah, I reached out to my child's teacher and she wrote back with a list of five suggestions, and we implemented them on day one and now we're all going to get ice cream as a celebratory treat because schools going so great. But the people who this episode is for, that's not happening. And so, yeah, there are options. There are steps that you can take even when it feels really hard. And we're going to obviously, as always, be speaking in generalities. This is not probably going to be your exact journey, but we want you to know that you do have options and get an idea of what those look like, what are the things that you can Google or ask about or reach out about. And that's really what we're trying to do here.

Lori: Absolutely. And yeah, we just really want you to understand that you can make such a difference when you have the knowledge. It's so empowering that you can be an advocate for your child and you can really do a lot to support them when you know your rights.

Katie: Yeah. And that's really at the heart of everything that we do here. Like, we created The Childhood Collective because we wanted parents to feel like they know how to parent their kids, how to navigate school. And so, it is at the heart of absolutely everything we do. It's not that we know what to do, it's that we want you to feel confident that you know what to do.

Lori: Absolutely. So, the first thing that we want you to think about is if you haven't yet, having an open, kind of respectful conversation with your child's school team about the things that you're concerned about. And I say that just because we see so many parents that, it is hard to speak up when you're one parent in a meeting with, you know, sometimes 12 other professionals and you feel like, well, they probably know what they're talking about so I feel uncomfortable saying that I don't like this or I don't agree with this. It's very hard to stand up and say that. So, I'd say if you feel like you haven't been super clear about what your concerns are, ask the school to schedule a meeting and come in, like, you know, ahead of time, write down all of your concerns, bring, you know, some information with you. So, if you're concerned about writing, for instance, bring in writing samples, bring in work samples. If there have been lots of behavioral referrals and you're really concerned about that, bring all of that information in. Emails from the teachers about those concerns and things that the school's done or hasn't done and really try and have an open conversation to say, this is what I'm seeing, these are my concerns, and put that out there. And again, that's really the first step. We really want you to be on the same page as the school team. And that really does sometimes require you to kind of document and bring in documentation and go to them and just have that open and honest conversation.

Mallory: Yeah, And I think something to keep in mind too, is when you make that request for the meeting, like, let the school know what you're asking to meet about. Like, don't just say, hey, we need to have a meeting. You know, be really clear about what you want to discuss at that meeting, what your concerns are, so everyone can come prepared for that meeting and hopefully have a productive and respectful meeting.

Katie: Yeah, I love that advice too, to make sure you're putting it in writing. And I think I've told this story on the podcast before, but I remember talking with a mom and asking her, you know, so have you guys gotten the evaluation at the school? And she said, oh, yeah, I asked them and it's been several months. And I said, okay, who did you write to? And she said, well, I stood at the front desk and I told them I wanted an eval and the secretary or

receptionist jotted that down on a post it note and stuck it to someone's computer and I haven't heard anything back. And I remember just being like, okay, step one is we're going to write an email to formally ask for that, because no one knows where the post it note is, right. And so, it is really important to put those things in writing. And I think just don't use the post it note strategy. I love post it notes, but not for requesting an evaluation and writing.

Lori: So, I actually had a parent write on a napkin, I think my child has dyslexia. And I remember the admin assistant coming into my office and she's like I think this is technically a request for an evaluation. And I was like, yeah, it sure is.

Katie: That's, good that she did that actually, because I don't think the blue post it note made it that far in my scenario.

Lori: So, I've seen a napkin, I've seen napkins, post it notes, whatever, but it's in writing. And that is such a great point, Katie, that, so many times I will talk to parents and they're like, I had a conversation over the phone even when they're requesting something like an evaluation and they just said, oh, we don't think we need to do that. When it's not in writing, it's not held to the same kind of legal standards. And all the things we're talking about today are based the law. And I know it feels so formal and a little obnoxious. but it is really important.

Katie: Yeah. And you can follow up. I mean, if a phone call is better for you, that's fine and then you would just follow up and say, hey, per our conversation today, I wanted to just quickly outline the things we talked about, you know, and you can put exclamation points in there so you don't seem super over the top. You can be very friendly. But the idea is that you want to make sure that, you know, things are documented and that really is the legal record. And by the end of this episode, it'll make more sense why we're saying that, because again, these are the situations where it's not going well. And yes, we do need to have that documentation.

Lori: And then another option along those lines is sometimes if you feel like you're not being heard or you go to that meeting and you sort of get brushed off, or you're still not in agreement, you can request something called mediation, which is an easier kind of lower-level support. And we're gonna, again, as we continue this conversation, there's gonna be options that are much more stressful. This is like a low stress option that many families that I've worked with have found helpful. It's basically a third-party neutral person will hear both

sides from the school, from the family, and then they work with you and, and the school to work towards a solution that you guys can agree on. So sometimes it's just even having that kind of neutral person in the mix can just make it a little bit easier to kind of facilitate problem solving in a situation like that. So that is an option to you and something that you can request.

Mallory: So sometimes even with that communication and mediation, things are still really tough. And that might be a situation where you would consider getting an educational advocate. And we've seen educational advocates really be a game changer for a lot of families, especially as they kind of move up through these tiers of like, next level of intervention, next level of intervention when things are not working. And an educational advocate is basically someone who knows these school laws very well. They speak the special education language and they will help you prepare for these meetings and help you more clearly communicate your concerns, your child's needs. Which I know can be so hard when you show up to those school meetings. You might leave a school meeting feeling like you didn't even get to share what you wanted to because your mind went blank or the school was going down a different direction and you didn't circle back to what you wanted to talk about. So especially when those emotions are high or you feel like you've hit a wall, a special education advocate can help with those meetings, especially as you're moving up kind of an intensity and stress levels. And you would pay for a special education advocate in most circumstances. There might be some nonprofit organizations that offer that as a free support to families. But that's one thing to consider if you feel like you're really struggling with navigating this process or being able to communicate your concerns effectively.

Katie: Yeah. And to find that person, often, you know, googling people in your area can be really helpful. Talking with other special education families or other families who have had similar issues. It's definitely, different advocates have very different personalities. You want to find someone that's a good fit for you and maybe even, you know, calling around and interviewing a few people. But you would essentially, yes, like Mallory said, you'd be hiring that person to help guide you through this process. And their name is so self-explanatory, like they are there to advocate for you and for your child. And yes, there is a cost, and that may be a barrier for a lot of families, but at the same time, there's cost in all of this, right. If you're having to leave work multiple times a week to go pick up your child because they can't stay at school. So, it's just weighing that all out. And you know, as Mal mentioned, there might be

nonprofits, there might be grants and things like that, but that's going to be very specific to your area. But that's just some ideas if you're looking for an advocate and kind of wondering, like, where do I find this person?

Lori: And, and sometimes it's just I've had many families that have a friend, or know someone that has been through a lot of meetings, like maybe they have an older child, they've been through the special education process for many years. And that friend, might just come to the meeting again to be there as a support and they maybe understand the law and can advocate with you. And that's a free option to you if you know someone or some people are just willing to do that to help another family out. The other option, and again, with an educational advocate, it's not a specific degree that you have so you do want to kind of look at what their background is. Many of the advocates that I've worked with have been special education teachers and their background or their professionals that have worked in the schools in some capacity. Some are just parents that have been through many meetings with their children and they've kind of learned and they're, you know, they've made this into a career. The other option is a special education attorney. These are very hard to come by. It's a very niche, you know, skill set for a lawyer. But there are lawyers out there that specialize within special education law. And again, they're going to have probably a much better background and, and we'll talk about some of the options later on where we would say this might be a good option for you to look maybe for an attorney. But again, it is a more expensive option too.

Katie: Yeah. So just to kind of review, you know, we're going to meet with the school. If that's not working, we can potentially bring in a mediator. You have advocates, and kind of at the top of that list is a special education attorney. So, let's look at a couple specific scenarios. Let's say that your child is on a 504 plan. And if you're not sure what a 504 plan is, please go back, check out episode 165 and we amazingly clear that up for you. We tried really hard to keep it really engaging. So definitely check that out. Let's say your child is on a 504 plan. You know what that means, but you don't feel like their needs are being met. So, your first step, as we talked about in episode 165, is that you're going to start with talking to your child's teacher and their educational team. So, most schools have a designated 504 coordinator. Many times, that's like an assistant principal or someone maybe on the curriculum side. And you would ask for a meeting with them and your child's teacher and work together to kind of figure out what's going on, what are the problems that we're having

and what are some solutions. And keeping in mind, you want to document that, you want to put dates on things, put things in writing and that just really helps keep track of what you've tried and where it may or may not have gone off track.

Lori: And the other thing I would say here too is this can apply to even if you don't have a 504 plan. So, many of the issues do come up where a parent is, you know, their child has an evaluation, they've been diagnosed with ADHD, they're going to the school and the school saying we don't need to put a 504 plan in place. Or they are concerned because they think their child might need a 504 plan and they need an evaluation, but the school saying, hey, we don't do an evaluation for that. So again, if you were in that situation, maybe you don't have a 504 plan, this can still apply to you. You can file a complaint with the Office of Civil Rights or the OCR. So, this is a formal kind of step to report discrimination, against, or discrimination, against a child with ADHD or potentially having ADHD, that the school is kind of not following through on the proper steps. And we talk a little bit about this in episode 137 which is the seven things all parents should know about their child's rights at school and it's specific to ADHD. And we talk about there being thousands of OCR complaints specifically for kids with ADHD because this is such an issue that kids are not being evaluated properly, that 504 plans are not being put in place properly. So, we do feel like that's a great episode if you are having this particular issue to kind of go back, and look through. But that is an option to file a complaint in that way.

Mallory: Yeah. And I just want to add the quick caveat that, like, not every family is going to need to file an OCR complaint if they feel like their 504 plan isn't being followed. It's not something that's always necessary, but it's important for you to know that that option is there if there's this communication breakdown and you feel strongly that the school is not working with you and your child's learning is impacted.

Katie: Absolutely. And that is what we talk about in that episode more in depth, is that because of those complaints and the sheer volume of how many parents had to complain, that's when you start to see policy change. And that's when the OCR released an entire statement with very specific requirements. The school does need to identify kids with ADHD. The school does need to provide accommodations and very specific things. And that is just such a great example of how our voices can be heard. So, if you are having a challenge and

you're not able to get your needs met, definitely don't discredit that and say, oh, there's no point, right. Because that is how change happens and that's our job as parents is to advocate.

Lori: Right. And we really wanted to talk about that again, so many families come into my office with the same issues over and over again to know, hey, it's not just you. This has been a, this has been a kind of a, problem within schools for a long time. So much so that they, the OCR had to kind of release this guidance to schools because we're getting, we're having so much discrimination against kids with ADHD. So, it is a very important episode and thing to look out for. Now we're going to focus a little bit more on if your child has an IEP. And this, there's so many different scenarios that could go on here. And I want to speak to some people are maybe going to be listening and their child's in a private space school. A lot of these things are focused on public or charter schools. However, you know, maybe your child went through an evaluation through a public school district and that is an option to you. Even if you are in a private school or homeschool, this is an option for you as well. So if, again, sometimes when you go through the process of getting an evaluation, you don't agree with those results, you don't agree with the recommendations. Sometimes your child has an IEP in place and this happens many times. Parents are coming in and saying, my child has an IEP but they're still getting failing grades. They're still getting constant behavioral referrals. We're still getting suspensions because of behavior. So, something still isn't working properly within this, right. We want you to know there is an option to you which is called an independent educational evaluation. Again, when we talk about that, those procedural safeguards, that, big packet of white paper, this is within the law it is a right that empowers families to be able to get a free outside evaluation by a private professional at the school's expense to identify, like, where is this child at? What are their needs? And get recommendations that is through a third party that is not the school district. Okay. So again, this can be if you are homeschooled, if you're in a private school and you've done an evaluation through a public school or you're in a public school, this applies to any and all of those circumstances.

Katie: Yeah. And this is actually how we all got to know each other. We all worked in a private practice where we did IEE's, independent educational evaluations. And we did several a week, you know, and we would all sit around the conference table, and obviously, I was on the speech and language side. Lori and Mallory were on the psychological side, doing all kinds of academic testing, cognitive testing, behavioral assessments. And we would come

together and we would say, okay, here's the situation. You know, the school has the parents say this child has been diagnosed with autism and they want services and the school is saying, this child does not qualify for any services under that eligibility. And so, we would sit there together and we would look at our findings and our testing and all the rating scales. Essentially, we were doing kind of redoing a lot of what the school testing had shown, and we were checking to see, is that consistent with our results. And there were times that we would agree with things that the school would say. There was times that we would agree more with the family. But ultimately, we were able to work together on these assessments and look at all these different aspects of development, and then we would go into that child's meeting and explain our findings. So, if you're thinking, like, who could do an IEE, what would that even look like? You might get to work with people like us who have a lot of experience with testing and diagnostics and would be able to really explain things and break them down. And again, that's at no cost to the family. That's something that the school has to provide.

Mallory: So, if you're still wondering, like, are you talking to me? Do I need to request an IEE? Let's talk through some possible examples of the families, you know, the different situations where it might be time to request an IEE. Okay, so let's take this example. Your child has a diagnosis of ADHD from the pediatrician. So, your next step is to go to the school to request some support because maybe you're noticing they're struggling with homework, they're bringing home a lot of incomplete classwork, they're getting recess taken away for misbehavior. So, you come to the school and you say, I'd like this evaluation. And they do that evaluation, and they say, grades are fine, they don't need any extra support because they're doing well enough. They're not failing, grades are fine. So you don't agree with the results of that evaluation because you see your child is really struggling. Yeah, grades are fine, but they're struggling in so many other ways. So, you disagree with the team's determination that your child doesn't need an IEP. That's one situation where you can request a second opinion, an IEE.

Lori: In other situations that I have seen, again, your child might, you know, the school agreed that your child needs an IEP. They've been on an IEP, maybe for a year, two years, five years, but what parents are seeing are continued behavioral referrals. Continued failing grades in subjects. Maybe they're failing in math, but they're not getting any math support within their IEP and you're kind of going and saying, hey, why are they not getting math

support? Like, this is a problem. So sometimes it's a matter of, like, they've done the evaluation. Maybe you agree with the results of the evaluation, but you're not agreeing with the level of services. And that's another situation in which you could kind of go back and say, hey, I'm requesting an independent evaluation to kind of see what my child's needs are because I do think that they've shifted and changed. So that's another kind of example or situation. Again, if you're, like, completely lost with our examples or feeling like I feel like maybe I do need an independent educational evaluation I have so many questions, we go into much more depth about how to do this and the how to's of that in our online course *Shining at School*, which again, is really much more in depth on how to empower you, your rights, the process, much more how to with the school. So, we give lots more guidance within that, so make sure to check that out, we'll put a link in the show notes.

Mallory: Yeah. And in *Shining at School* we also have a template, a sample letter that you can use to even request that IEE and we have a whole section on our most frequently asked questions when it comes to these kinds of things to kind of help you problem solve your specific situation. So, okay, moving forward. So, let's say you've tried all of these steps and you and the school are saying, still not agreeing on services. Maybe the school is suggesting that they need to put your child in an alternative placement and you don't agree with that, or you don't agree with the placement they're recommending. Or maybe the school is still saying your child does not qualify for any kind of special education services. You have a couple options. Again, this is like top tier. This is when you've tried all of these other things and you're still feeling like your child is not receiving the support that they need. One thing you can do is you can file a state complaint with your state's department of education. What you would do is you would share historical information with them. Again, you've been documenting all of these things all along and so you're sharing that documentation with them and you're filing a complaint at the state level. And then kind of this top, top tier option, which is basically like going to court, is you're filing a due process complaint. This is a formal legal proceeding. You need a special education attorney to help you when you're at this level because as I said, it's a legal case, it's going to court. And in this case the lawyer would walk you through how to clearly outline what the school has done, how they've violated the law, share any relevant testing that's been done, recommendations that have been made. And again, this process is really intense. So, you need a lawyer at this level to walk you through this process.

Lori: And I think you can also have an educational advocate that can walk you through too. A lawyer is just going to be, they're going to have more experience and background, but you can also use an educational advocate. We would really encourage against doing this on your own though because it is just an intense process. And again, many families that I've talked with in the past about, like, this is kind of the next step. Like, we've done all these other things, this is the next step, have not done that just because it is a very, you have to understand it is going to be a stressful experience. Anytime you go through something like this, it is stressful, and you have to understand that.

Katie: And I was saying too, you know, we've done a lot of these IEEs over the years, and there have been times when we present our findings to the school and they don't agree, even though our testing was amazing and how dare they? But in that case, you know, even beyond that, then the lawyers would say, it happened to me twice, actually in six years, where they would say, okay, well, you now need to prep for due process. And I'm like, oh, my goodness. Like, I don't want to do it. But they would bring in, you know, the specialist, whoever did that testing other people like that, but in both of those cases, it ended up that we didn't go all the way to due process so the school doesn't necessarily want to go to due process either. So again, like we've said, it is kind of a last resort situation. But if you are questioning, like, I get this IEE, what would happen next, that's your answer is in, you know, if all things don't move forward, it would go to due process.

Lori: Yeah. And it is, it is an extremely expensive and time-consuming situation for the school. And they do want to avoid that at all costs. I mean, but again, you know, sometimes it does take going to that level to see change happen. And so, we want parents to know that that is an option to you.

Katie: Yeah. So, we're deviating a little bit today from our normal, like, host a movie night content, work on executive function. It's so great.

Lori: This feels so serious.

Katie: It is serious. It's kind of interesting, right? Because if you've listened to the podcast for a while, you think of us probably more as moms and really creative problem solvers, but this is our professional hat where we would all dress up for work and sit at this big table and do these things. And it is fun, actually. I kind of get excited about it because I haven't done this

kind of testing for a few years and I'm like, oh, yeah, it was super awesome, actually. When you really, like, peel back the onion and get to the heart of what's really going on with this kid, how can we support them? And it's definitely a labor of love.

Mallory: So, if you loved today's episode, even though it was a little heavier than our normal ones, please take a minute to leave us a five-star review wherever you listen to your podcasts and today's takeaway is that you have a number of legal rights and options if you disagree with the school about what your child needs to be successful. Understanding your rights, your child's rights, and taking proactive steps can help you advocate confidently and ensure your child gets the support they need. And as always, we're here to support.

Katie: Thanks for listening to Shining with ADHD by your hosts, Lori, Katie, and Mallory of The Childhood Collective.

Mallory: If you enjoyed this episode, please leave us a review and hit subscribe so you can be the first to know when a new episode airs.

Lori: If you are looking for links and resources mentioned in this episode, you can always find those in the show notes. See you next time!