

Ep #108: IEP Refresh



Full Episode Transcript

With Your Host

Lisa Candra

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You are listening to episode 108 of *The Autism Mom Coach*, IEP Reboot.

Welcome to *The Autism Mom Coach* podcast. I am your host, Lisa Candra. I am a lawyer, a life coach, and most importantly, I am the full-time single mother of a teenager with Autism. In this podcast, I am going to share with you the tools and strategies you need so you can fight like hell for your child without burning out. Let's get to it.

Hello everyone and welcome to the podcast. For this week's episode I am going to be playing an abbreviated version of a previous podcast, episode 57 with Amanda DeLuca and Kirby Morgan, both who are mothers of children with Autism and IEP advocates. I wanted to play this recording for two reasons. First, I want to give you an IEP reboot before next week's three day IEP bootcamp that I am posting on my Facebook group page, the Resilient Autism Mom group.

And second, I need some time to prep for next week's three day event. So if you are interested in learning more about the IEP process. If you want to get tips and tricks for someone who has been at the table for 14 years and you want to be in community with other mothers who are asking questions that you may need the answers to. You want to join my Resilient Autism Mom group on Facebook now.

This is going to be a members only presentation. So once you are in the group you will be able to come live. You will be able to ask your questions beforehand, during the live sessions. And you will have access to the replays. You don't want to miss this. I am going to go beyond giving you the basics. I am going to tell you what the most important tool you need to have, your most important weapon, your most important resource at that IEP table. And I'm going to give you some very specific examples that I am going to draw from my client coaching and my own experiences.

In the past month, in addition to the IEP meeting for my son, I have been coaching my clients every day about IEP meetings, clients who have children who are in the 18 to 22 range and depending on their state, they are transitioning. Or as we sometimes call it, falling off the cliff and

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everything in between. So if you have IEP specific issues, you want to come to this.

And even if you don't, the things that I'm going to talk about, the tactics I'm going to talk about, the strategies and the tools, you really can apply these to everything. Maybe it's a conversation with the doctor. Maybe it's even a conversation with people in your family or friends, what I am going to teach you in this three day bootcamp will help you with all of it. So again, go to Facebook, join the Resilient Autism Mom group and start asking your questions. I can't wait to talk to you. I can't wait to hear from you and I am excited to get you as much information as I can.

And a bonus, for whatever questions I can't answer during the live, I will get you the answers. In fact, the following week on the podcast I will be interviewing a Connecticut based special education lawyer. She is a mom who has been on all sides of the IEP table. She has been the parent. She has been the principal and now she's the attorney. So my interview that's coming up with Melissa Gagne following the IEP Reboot is going to be so informative for all of you. Again, for whatever questions I can't answer, I am going to post them to her on the podcast.

So final call, go to Facebook, join the Resilient Autism Mom group and I can't wait to see you there. And with that, let's get to the IEP Reboot with Amanda and Kirby.

Lisa: Welcome Amanda and Kirby to the podcast. I'm so glad you're here. Let's get started by having you two introduce yourselves. Amanda, would you like to go first?

Amanda: Sure. So my name is Amanda DeLuca. I live in Ohio. My son Jackson was diagnosed with Autism at the age of two. And I had previously only been a dance teacher, that was my full-time job. And then once we started exploring how to support my son I learned that I needed to know more in order to better serve him. So I became an IEP coach serving

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families at the table just because I wanted to know more for myself and it grew from there.

Kirby: Hi, I am Kirby Morgan. I live in Menifee, California. I have two sons who are neurodiverse. My oldest son, Jayden was diagnosed at two. He is now 12, which is hard to believe. And Jackson is nine, and he's just walking through his ADHD diagnosis now and we're working to understand it and how to cope with it. But I became an IEP advocate when my son was at age five. It was our transition from our safe preschool to now the big kindergarten where I really noticed that dynamic of the team or the dynamic of openness.

Amanda: When Kirby and I met, Kirby was the angry advocate and I was, "But we can work together." And I'm like, "You need to take this course. I promise you, you can work with the team and still get the same result." And she's like, "I don't believe you. So I'm going to take the course and then we'll come back and discuss." And she was like, and here we are.

Lisa: And when you say course, are you talking about the training?

Amanda: Yeah. So, Kirby and I are both a part of the Master IEP Coach Network. And we both went through the Master IEP Coach Mentorship because I was rainbows and butterflies when we were helping parents and Kirby was like, "But the law says." We learned there was a middle ground, and that we offset each other nicely. So we became collaborative.

Lisa: That's, yeah, listen, I won't say good cop, bad cop but there is certain roles to be played by all. So, Kirby, when you're talking about researching the statutes and things like that, I mean that definitely resonates with me because I too am an attorney. And one of my struggles as a parent is the disconnect between, yeah, the law might say that, but this is actually what happens in my district. And that frustration of that disconnect, can you speak to that?

Kirby: Yes, because it's a huge pill to swallow because it's not the way the law reads and I know you know this as an attorney. It's very interpretable.

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However, any interpretation of what this statute says is not, this is not what is happening in my kid's school. When I walk in, that's not what I see. But I had to really drum it down, Amanda helped me with this, to see it as, is my son's needs being served? Is my son seen? Is my son getting the services he needs? Is this working? And it was really, really hard because I know I could be in Due Process 1,000 times a year, but where is that going to get me?

That was the hard realization for me, because it was either going to be a Due Process every time because the law was the law, and secondly, they were breaking it and I could prove it. But how was that going to serve my son going forward? And that was the hardest part. And that was the biggest, once she told me about the course I was like, "Okay, I'll take it, but I'm not buying it."

Lisa: Well, I think I'm in complete agreement with you. And I have this conversation with so many of my clients who come across an issue where it is clear that there is a discrepancy. But it's always like is the juice worth the squeeze? Is the amount of energy, time, resources that you put into this, what's the net result going to be? Is it worth it? Can we get it another way? And it becomes the difference between being right and moving forward in a way that's sustainable.

Amanda: Well, and the pandemic has really shown us, there are other ways to support our children that were not written out in IDEA law, that we've really had to sort of adapt and move forward. Because we were living in times that we had never seen before. We're living in staffing shortages where we have to get really creative with how we're delivering services. The service is still being delivered, it just might not be by the book old school. And Kirby and I say that a lot, "Are you an old school advocate? Are you a new school problem solver or problem solvers?" That's our job.

Lisa: Yeah. So when it comes to the IEP table, one of the struggles that I have is that I just want to be mom at the IEP table. And the fact is, is that we play so many other roles, advocate being one of them. But for the two of you, you are actually professional advocates. So I'm just wondering how

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that plays out when you're sitting at the table with your team and your interactions, do they know that you're an IEP advocate? Do they know that you know what you're talking about and that you can back it up? Tell us a little bit about how that goes for you.

Amanda: So my son's school knows what I do. I am not secretive about it. I am not hiding it from anyone. And I have served other parents within my home district, not so much our private school but with our home district. The administration is usually the ones who say, "If you're not doing anything wrong, you have nothing to be worried about." Her job is to come in and make sure that we are doing everything the way that we are supposed to.

With my son's own team, I tell them from the very beginning, "I want open communication. I'm going to send you a parent input statement", which Kirby and I tell all of our parents to write these, submit these. "I am going to be very forthcoming with you. I do expect a copy of the draft before the meeting so that we can work through and iron out a lot of the questions and discrepancies so that our time at the table is short. I respect your time. I know you need to be in the classroom. Let's work through this the best that we can."

Not every school is as open to me coming to the table, but because I am open and honest with my son's team, we have a really good relationship. That doesn't mean I don't push back, and, Kirby, the same with you. It doesn't mean that you don't push back. But Kirby and I also consult with each other so that we're never coming to the table just by ourselves. We're never coming to the table from an emotional standpoint. I called her on the way into my IEP last Thursday and said, "I need to run this by you really quick to see if it's garbage or if I'm just being emotional."

And we have to do that because I can take the emotion out of advocating for other people's children all day long. When it's my own child I'm still working on that skill, five/six years in. So there's no perfect, but there is being honest and open and having good communication that really helps break those walls down.

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Lisa: I love that. And one of the things you mentioned and we will circle back to that later is the parent input statement because I think that that is such an important piece of the role that we play and so many of us don't even know about it until our advocate tells us. Okay, Kirby, how about you?

Kirby: So here, my husband is retired Navy. And so we moved a lot depending on where my husband worked. So very quickly I both served as advocates for clients and attended IEP meetings for my son in the same districts. So even before we moved to where we just moved and built our house, I knew the team, most of the district team before I came in as a parent. So a lot of them know me. It's no secret. And I think that it is so much easier to advocate for a client than my own son. I think I know my son so well, so when things are said that I don't agree with, I take it so much more personally.

And I always try to have my husband go, number one, because he's the complete opposite of me, he's real laidback, he's like, "Okay, Sue." He's real nice back. If I'm getting a little bit too, because I can argue, not to say I like to be right, but I like for my points to be heard and acknowledged. And sometimes in those meetings when we're at a district remit, my husband will stomp on my foot or like, "Turn it down a little bit." It is a lot harder. But I think that as long as the team, I have now a reputation where they see me on the team and they're happy that it's not a different advocate.

Because they know I'm there, because we all at the end of the day have the same goal. We want to work together. We want this to work. Nobody wants to stay in five Due Processes. Nobody wants to go to mediations because it just takes time. And that's time that the student is not getting what they need. So I think once the district team really gets to know who you are as an advocate, the respect is always there and it's always mutual. I'm always welcome.

Amanda: I think we've grown in our practices and in our skills because in the beginning for me my advocacy was quantity over quality. I wanted more minutes, more services, more. Now I can take a step back and look at what is attainable, what is truly beneficial? What is the appropriate amount of pull

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out services, push in services, small group. And that's just growing and that's just the growth process.

And learning that and being able to work with the team by looking at the data, the time and the day, what the child truly needs. That helps us become more welcomed and more respected than like I said about Kirby sometimes, a dog with a bone.

Lisa: So I want to shift a little bit from being an advocate to hiring an advocate. Because one of the things I hear from folks about this decision is they are concerned that it will negatively impact their working relationship with the school, that they will be offended, that they're no longer going to be friendly, that they could take it out on them or their child. How do you respond to that?

Amanda: So to me, hiring an advocate is not the same as saying, "We are going to Due Process. Saying. We are going to Due Process means I am not willing to work with you. I don't hear your point. I don't think you're doing your job appropriately." That to me does change the tone because your team no longer is communicating with you. You're now talking directly to admin. Bringing an advocate to the meeting as a secret, changes the tone of the meeting. We like to let the team know we are coming, put us on the invitation, let them know we are coming as parents support because that is our job.

It's to make sure the parent understands what is being discussed at the table, that they are comfortable with the decisions being made and that they are ready to move on. To make sure that someone is taking appropriate notes so that if we come to a disagreement that it is documented. That is how Kirby and I handle an IEP. There are old school angry advocates, "You're doing this wrong. It can't be written that way." And there is a time and a place for that.

But if you reach out to the team ahead of time, like we tell our parents and clients to do, to ask for the draft copy, to look for the parent input statement. We are trying to build a team that is all working together for the

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child instead of, let's hold all of our secrets back, let's drop these bomb shells at the IEP table. Let's not let them know what we're asking for. That creates a divide in the table. Kirby, what do you think?

Kirby: I agree. I think that open line of communication when you hire an advocate is very important. Hiring an advocate is different than saying, "Hi, I hired an attorney." Because there are attorneys that will go and sit at these IEP meetings. So I think that's a different tone, but I do think that the term 'advocate' has gotten a little bit of a negative connotation because there are a lot of advocates that go in there and nitpick the document versus try to work with the team to create a working document that's going to serve the student.

Lisa: Yeah, that makes sense. And so I think what I'm hearing, part of what your answer is, know your advocate and who you're hiring and what their reputation is for working with your school district?

Kirby: Right. And you can usually tell. I've been to many, many conferences and I used to be a part of [inaudible]. And you could tell, when you talk to someone and the way that they present a plan, an action plan. Amanda and I like to have an action plan for our clients where we have a consultation. This is our action plan. If that action plan is going in there with guns blazing, that's a red flag for me because that's going to get you nowhere fast because it didn't get me anywhere fast, trust me, I tried it. It didn't get me anywhere.

And I had to learn a better way and now that I practice differently, I see that you get so much more with just that little shift in willingness to collaborate instead of it being you versus them, making it us, it's all of us, we are a team here.

Lisa: Right. But still, I'm thinking of the parent who's a little bit squeamish and a little bit afraid. I have heard from clients when they show up with the advocate and it is presented to them that there will be an advocate, there is a little frostiness. And personally what I say is, "It's fine, it'll pass." They can feel however they want about it but your job is here as the CEO of the

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team, your child, to advocate for them. So it's okay if other people don't love your decision, they will get over it. But I just want to see if you guys have seen this in real life where the team is kind of like, "I thought we were working well together and now you've brought this person to the table?"

Amanda: Well, and it's not so much that but parents usually call us when they have tried to handle it for too long and it's gotten too far. It's not, we're heading into IEP season, we want to work with the team to get the best document that we can. It's, I don't think my child is getting services, I'm getting calls to come and get them from school. Their behavior in the classroom is preventing them from being in gen ed, now they're pushed to self-contained. They're not getting to be placed in the district I want them in. It's not, let's come in and make sure everyone's on the same page. It's crisis.

Kirby: No. It's, "Hi, we're in crisis mode and we need to hire you, we need help." A lot of the times we walk into that.

Amanda: That's where the frostiness comes in, because everyone is already on guard. You said this, I'm hearing this, I think this. And we're trying to pull all the pieces of the puzzle together and figure out where we can find common ground, where we can bring everybody back together. And that's not making the school happy. And that's not making mom and dad happy.

That's making sure that this document serves this child the best that they can because sometimes that means everybody has to compromise to get it on paper. Because what I want may not be exactly what our child needs. And it's that quality of life over your ego. And your opinion is where we really have to hone in on what does the data show. What does the school actually have for support? How can we make this the best environment possible? And if we can't, then that makes it even harder because we're saying, "What are our other placement options?"

Which is where a team doesn't love to have those discussions. It's not me saying you as a teacher, it's not me saying you as a speech therapist. It's

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saying this child needs behavior support. This child has medical needs that are not being looked after. We need to look at where else can serve this child better. So that you can continue to serve all the other kids in your classroom, so that mom can feel better about sending her child to school. It's when we're called in, in crisis mode that we get that, all hands are up and no one is happy.

But that's why hiring an advocate from the very beginning helps you build those relationships, keep those relationships, keep the communication open. And then it makes Kirby and I's job so much easier because we're not just putting out fires. We are really building everything from the ground up.

Lisa: Yeah, I've definitely had that experience of having an advocate who's followed me over some time and seen transitions from school to school. And has a working knowledge of the progress and the relationship. It does make things for sure easier. And I have also hired an advocate in crisis mode. And oh my gosh, such a lifesaver to have somebody else taking on that role as I was dealing with all of the other stuff.

So one of the questions I have for you guys since you do sit on both sides of the table simultaneously is, what lens do you view the relationship with the school districts, viz-a-viz the school districts and the parents? Are we all on the same team? Is it us versus them? Is it somewhere in between?

Amanda: So my experience is parents feel that it is us versus them because the communication lines typically are not completely open. Kirby and I, not being that child's parent coming to the table can see how we build everyone together. That is our goal always, to create a collaborative team environment, to make sure the parent is being heard. To make sure the team is being clear and transparent and to really build that back and forth conversation. Our goal is to coach parents so that they don't need us forever.

There are some parents who want us forever and that is great. But I want you to feel empowered. I want you to feel like you are in control. I'm not

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sending every email on your behalf, neither is Kirby. We are helping you build documents. We are helping you write letters. Those emails are coming from you. We will be there to help you but this is still your child. You are the head of that team. You sit at the head of the table and we want you to feel comfortable doing that because that's what we needed as parents. So those are the services that we are providing for families.

Kirby: Yeah. And I think our goal is for it to be a team. And I think a lot of the time when we walk in, it's very much us versus them. But I think the reality is it ends up somewhere in the middle. But the goal is always for the team to be completely collaborative because we do want that transparency. And we want the parents to feel like they know what's happening. Most importantly, the number one thing I get called for, Lisa, is parents have no idea what is happening once they drop their kid off at school. They have no idea until they pick them up.

And then months later an incident will happen and that's when they want to hire me. And they just throw you in and it's like you have to figure out and there's just so much missing information. So I feel like parents kind of have to really start making sure there's communication because without communication there is a lack of knowledge of your kid's school day.

Lisa: Well, how does the parent make sure that there's communication, just assuming that the parent has asked the questions and maybe not received the feedback?

Amanda: So I have a top three with clients. And one of my top three is communication. So you need to ask your team what is their preferred method of communication. I prefer email because I don't want to answer my phone. But if I'm emailing a teacher who doesn't check her email, that's not good communication because I didn't ask her what her preferred method of communication is. With our older kiddos, Kirby's son is about to go through this transition phase again because he's older.

I don't want a piece of paper coming back and forth because at Jayden's age, Jackson's going to hide that in his book bag because he knows how

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his day went. He's probably not going to want me to see it. Is it through an app? Is it through an email? And Kirby and I use this example that I've used since day one. I don't need to know that he made a macaroni necklace. I don't need to know that he preferred blue Jell-O over orange Jell-O. I need to know, did he keep his hands and feet to himself? Did he stay on task? How many times did you have to redirect him?

Did he complete his work independently? How modified was it? Those are the things that I need to know. So I am very upfront with my team, here's what we are targeting right now. I want it broken down into the block schedule of his day so that I know if we are seeing behaviors, during what time are they, during what subject? How do we work through it? And I also want to know what the consequences were. Because I can tell you, withholding recess is never okay with any of my clients. So if that's written on a paper it's time for an emergency meeting.

I am very clear and write that into the IEP. I need daily communication from school and you will get the same respect from me. If he didn't sleep last night, you're going to know about it. If we had a med change, you're going to know about it. I am going to be equally as transparent with you so that we can work together. So that if you're not getting that daily sheet, let's say it's been one day, things happen. Three days, we need to call the team and say, "We need to have a meeting because it's written in, I need to know what's going on."

I'm not a big fan of secrets so I just lay it out, "Here's what I expect from you. Here's what I want written in." And if that can't be done you need to tell me exactly why so we can figure out what the solution is.

Kirby: And honestly, Lisa, I wish I could say, there was this magical place you go and it tells you these things but there's not because if there was, me and Amanda would have known because we're on Google figuring this stuff out for years because we wanted to best serve our child.

Lisa: Yeah, there is no tidy to-do list for every little thing. I mean for my son, I had the experience that when we first started out, his first school they

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always did the communication logs. But when we went to the next school in another state they're like, "We don't do that." And so trying to broker that because that was something that was really helpful for me. But had I not had it at my first school I wouldn't have known about it. And there's so many of these things that we do that we figure out because of figuring out what works for our children and then getting the team onboard with that plan.

Amanda: What's important to say though is they said, "We don't do that here." Show me the policy. You mean you've never done it before. Doesn't mean it can't be done. That means it's not what you're used to but it is individualized for a reason. Sorry.

Lisa: Yeah. No, absolutely, but what I was hearing from them is, "We're not going to do that." And then again, it's also is this the fight that I pick the first day of a new school in a new state? And so we did it their way for a little bit but then we ended up doing it my way.

Lisa: I also want you to answer the question, and maybe you do at some point during your tips, is when you and the school aren't seeing things the same, because you're literally not seeing the same thing. Say the kids [inaudible] at school and they come home and they're bonkers, what happens there? So let's just shift to some tips and let's just think about the parent, they just got maybe a diagnosis, they've just gotten the IEP and they're going into their first meeting. What would you tell that parent, not only for that first meeting but just in terms of the road ahead?

Amanda: So I think it's important to know that that IEP document is not being read to you to just say yes or no. In that first IEP meeting I think that's what it feels like for a lot of parents. Here is what they are offering, I have to take this. Your input, your data, your questions are a part of this meeting. You are an equal member of the team. I did not realize what that truly meant in the beginning. I felt like they were offering me the best that they had and I had to take it or leave it and that is not the case.

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And no one is going to tell you that, that comes from learning, doing your research, hiring someone, joining our community and doing the trainings that you should be in the process of developing this document with your team. Your parent input statement which is something else that if this is your first IEP meeting, you have not heard about, so Kirby, I'll let you talk about that. Should be submitted to the team ahead of the meeting to outline your expectations, your goals and all of that.

And also making sure the communication is outlined, making sure you know what are your top three priorities, what are you going to say okay, I'll give on. What is not a negotiable. If you are worried about safety, that goes in the non-negotiable. If your child has medical needs, that goes in the non-negotiable. But there are some things that we might have to be like, yeah, let's try it your way for a little bit. Let's agree to meet in three months and look back over it. That document is working and moving and changing.

It doesn't have to be signed and set for a year. You also don't have to sign it at that meeting. And I think that's another thing that people don't know going into their first one. So, Kirby, do you want to talk about parent input data collection? Because that's another topic that we love and not signing right from the get-go.

Kirby: Yes, I want to say first too, when I went into my first IEP meeting I had no idea what [inaudible]. My husband was like, "Do you want me to take off work and go?" I'm like, "No, no problems, [inaudible]. Jayden and I got this." I kind of almost felt like [inaudible] because I hadn't worked in a long time, put on my little blazer, my cute jeans, went in there. And I had no idea. They were so nice on the phone. They asked me a few questions about Jayden. I brought in a stack because I'm that type of mom.

Here's all the information from all the therapies and all the places. And I was flabbergasted at first of all, how many people were at that table that I didn't know and that I didn't know were going to be. Because it was his initial IEP and they didn't formally send the invitation. I signed the invitation at that meeting. So one thing I always want to stress is that you should

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know who's going to be at these meetings. It shouldn't be a surprise when you get there. And there's a whole table, I, Kirby, didn't know that.

Kirby just was like, "Oh, there's 12 people here." So then I sit down and I didn't realize how completely formal it was going to be. Because when you're entering the district with a young child, it seemed so friendly and we're going to work together, we're going to read all his reports and he's going to get everything he needs here. And it was just very reassuring. So then I get there, they lay it all out and they tell you to sign. And I'm thinking, these nice people, they're going to help my son, they have all these great plans, they have all this experience.

All of these experts. They know so much and you sign on the dotted line because you don't know better. However, what really happened was I attended a meeting for three hours and talked about all the things my son was struggling in and all the assistance he needed and all the parts of the charts that he was way off of. And it was very emotional and it was a lot. And a lot of things were added during that meeting and crossed out, the computer was passed around to these 12 professionals and the document was changed.

And at the end I didn't have the mental capacity to sit there and read it all but I signed it.

Lisa: One of the things you guys mentioned earlier was collecting data and parent input statement. And so give me an example of what data is, how you collect it and how you present it.

Amanda: So as you're at your first IEP meeting and they are reading you the goals and the objectives on how they are going to achieve the goals. There is a section that is often skipped over and it is the data and observation. This is checked boxes or a few different ways of collecting data that the team is going to decide upon. This section is often skipped over as if the parents don't have any input here.

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We want to make sure that you are getting appropriate measures of the objectives and the goal to show if your child is or is not making progress and that the time is being dedicated to this goal. So that could be classroom observations, work samples etc. So that when you are getting report cards and progress reports because that is part of your child's academic career, that there is data that shows you how they are doing, what percentage they are getting accurate and how it is moving along.

So make sure that you are taking a moment to pause, ask about the section and let the team know that when the progress reports come out, or the report cards that you want the data along with the progress report. So you are getting real life examples, and accurate information each four and a half or nine weeks, whichever you decide upon. But again, don't let them tell you, make sure you're having a conversation so that everyone is on the same page before you move on.

Kirby: This is something you could put into your parent input statement which is a very important document that you write. It's almost like a vision statement. This is my input for this school year and these are what is most important to me. This is what we are working on. This is what works for my child. And me and Amanda like to say, "It's not a dumping ground for all your complaints and all your concerns." It's where you get to the nitty gritty of what...

Lisa: Your list of grievances.

Kirby: Right. That's for somewhere else, that's for your journal, this is let's get down to the really strong points that we need to work on this year and that are very important to me. Because what's important to me may not be important to you. So it's really important you figure out what you want to see. So daily communication, data with your progress report. If your child is entering preschool and working on potty training and that's a really important focus, then maybe you want a log on that.

Or your child needs medication, that's non-negotiable that the nurse and you have communication and those types of important, important things.

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And since each child's different, it's really important that as a parent, you take the time to nail out maybe three to five points to write in your input statement and present to the team. And I would say as soon as, if you're going into preschool or kindergarten, as soon as you know who your new team is. So that there are no surprises and you are showing up with transparency because that's what we expect with them.

Amanda: I send my parent input about a month ahead. I know that we're going to be meeting. I know they're going to start writing goals and I want them to know what my priorities are, what has worked, what hasn't worked. So that as they craft the document they already have my input. So there's no too soon. But if you wait until the day of the meeting or the day before then it's not going to be reflected in the document. So just some timelines to keep in mind.

Lisa: Yeah. And I would add as somebody who has a longer history with this, my son's 15 years old. Is that in those parent input statements I will sometimes incorporate the communications we have already had as I've documented to you in the emails over the last three months. Because I am emailing that team every single day. If you just add up all those emails, I've written a book. And I know all of you have too. But to have it in that meeting because that really is the record. That's the official record. Our emails aren't so much the official record.

So it's however you can get your concerns into that document, it's really important. So, Amanda and Kirby, you're talking about collecting data. And one of the things I'm curious about is when the data that they see at school conflicts with the data at home. So let's just say that your child is staying regulated in school and they are having what appears to be a great day but then they get home and they're completely dysregulated. You're having a lot of behaviors and issues at home. How do you address that?

Amanda: So we're actually living this right now. So my son's home team is at school today doing an observation and of course it's perfect at school. So what we're looking at is what is their praise ratio? What is his block time schedule? How many choices are they giving? What rewards are they

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working for? What does the workload look like? Is your child melting down when they come home because after they've been at school in their home now they have to do homework? Then we need to look at reduced workload.

We need to look at maybe work done to mastery instead of all this extra busy work. Are they taking sensory breaks? What do those look like? At what point are we getting too far tipped? So having that communication and the breakdown of their schedule really helps look at that. How are they ending their day? Are they ending their day dysregulated because they know they have to get on the bus to come home? Then maybe that's a trigger point we need to look at.

But utilizing your home team with your school team helps them to see your child across all environments which is where we're at right now. School is perfect, home is chaos. He's kept so busy at school that he doesn't have time to go off track. Here I am not a cruise ship director, you are home, you need to occupy yourself. We have to work on teaching him some leisure skills and how to follow a visual schedule at home. So it's really being honest with your team and saying, "Then we need to look at where are they tipping off? Because we can't live like this." And that's okay to say.

Kirby: And sometimes the team may be utilizing some tools that really helps your child. And that's where communication is super important too. Say, "Hey, what are you doing to get through transitions that are a little bit difficult? What tools are you utilizing? Can you send home an actual visual like that? Because I would like to try it in the home front." Because that should be going both ways. And it could maybe really help if something's working at school because I'm of the mindset, try it, let's try it. If it's working there, let's try it out.

Lisa: Absolutely. And I have to say, especially with my son was pre verbal or barely understandably verbal. Those communication books were so helpful because he would come home and try to tell me something or communicate something that was related to school. And when I could go into that book and kind of figure out sometimes, they watched *Up* today at

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school, that's why he keeps pointing at the balloon or whatever it was. It was so helpful.

So the data and the parent statement, those are two really great tips. So for any of you who are new to IEP meetings or you've even been at them for a while, may not have known this. I know I didn't know about the availability of a parent input statement until I hired an advocate.

And so I want to keep on that track of what else would you want parents to know whether they hire an advocate or not when they're just getting started out and they're managing this process at first and then also over the years?

Amanda: So the first question that we always ask a client or advise a parent is reach out to your team and request the draft copy of the document. That way you can read over it, we can read over it with you, we can look at it and figure out what we want to change or adjust or ask questions about. Some states require a draft be sent. Most states send it as a courtesy. So it really doesn't matter if you live in a must or will, reach out and request it because it is common courtesy to have it sent to you. That is an email, that is not talking to your teacher in the pick-up line.

Send an email, let the team know that you are looking forward to your upcoming meeting so that you can come to the table as an equally informed member of the team, you are requesting a draft copy of the document so that you can review it ahead of your meeting.

Lisa: Awesome. Kirby, how about you?

Kirby: Well, here in California we are one of the states that it is a must state. And I have to say, even as a must state, if you are not asking for it, you are not going to receive it. So I think just keeping the open lines of communication and making sure that in your IEP document you really stress the importance of having your progress report include data. Because a lot of the time, you will get home a progress report and it will just say goals and objectives, nothing more. It will have the goal and say goals and objectives. You won't have a work sample.

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You won't have any sort of data that goes with it. So as a new parent I wish I knew to ask for that so that I knew that the progress that they're saying, "He's 60% towards his goal." Well, how do they know that? How are they figuring that out? I never knew that I could ask for his actual work samples and to show me how they're calculating that data percentage. And now knowing it, it's really important because it helps me see that he's really doing that or not so much and we may need to switch up this goal or modify it.

Lisa: What about the child who has had an IEP for a couple of years, they have their goals, they have their objectives, and they appear to be doing well. So you get to the IEP meeting and they say, "Oh my God, he's doing so well." And that feels so great to you, as a parent you want your child to be doing well. "You know what, we don't think he needs these services anymore", how do you respond?

Kirby: Number one, I don't think I know based on data. So if they're saying, "We feel, we think", red flag, meeting's over, thank you, goodbye, number one. Just have a great life, long and short of it.

Lisa: I'm sorry, were you the dog with the bone or is it that Kirby?

Amanda: Right. Well, if your team is thinking of discontinuing services as Lisa is talking about, this should read in that draft document that the team on the very last page where it says, right now my son's team thinks it would be detrimental to Jackson's academic growth to discontinue IEP services. A lot of times parents will see this for physical therapy and they'll say, "They don't need therapy anymore but we're going to move to consult." You have to consent to that change. So again, this circles back to Kirby, what does the data show?

What are you proposing as a change? When are we going to meet again to discuss this? Can we taper this off in six weeks, meet and see what the data shows? And a lot of times it's maybe moving from an IEP to a 504 which is a whole another conversation, but again, a plan to support your child. We need to look at what data did the team use to make this decision.

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Because if they think or they feel, we don't have that conversation, data drives all decisions.

Lisa: But even if there is some data to say the child is meeting these expectations, they are doing well, does that mean bye bye IEP? Because in my experience, I have seen my son do well, supports be pulled and then he's not doing well anymore. And so it's difficult with parents because on one hand we want to hear great things about our kid, we want to believe that all of the work we are doing is leading towards the result of maybe them needing less support. But at the same time I always fear that pulling that support too early could have more detrimental impacts.

Kirby: I think that it's never a great plan to just see services. And I think that if the data is supporting the child is moving towards more independence, or the conversation of tapering. Let's say this is a one-on-one aid and the child's not needing that support anymore, let's have the aid across the room. Let's change the distance. Let's change the way that the support is being provided to this student before we just remove it. And I feel like Amanda will agree with this statement. This is a little bit of our outside of the box thinking when it comes to IEPs.

Because in old school IEPs it was like they get the support or not, where here we're trying to change that narrative to let's see with a little less support how they do before we just yank off support. Because again, we want the kids to succeed. And every parent's goal is for independence, that is why we do all the things we do, but we also don't want to see the kid set up for failure when we remove the supports that they possibly still need.

Amanda: I think it's important to remember the purpose of the IEP is to support them educationally. It's to support them as lifelong learners for independence and for future employment or college or trade school. So let's say they are crushing their OT goals, okay, well, can they type? Because that's part of a life skill. Can they read a clock and organize their day? Can they remember to set a reminder on their phone? Do they know how to set a digital alarm?

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All of these things that are life skills that schools may not be used to providing but they are skills that our children need so that it's not, we're cut off from academic and now they have no life skills to function in the real world. So while we may be mastering the goals we have written now. Have we looked at the whole picture of supports that we should be providing before we're having this discussion of stopping an IEP?

Lisa: Yeah, that's such a good point. That's amazing. So just one last question, comment. One of the things that I hear from parents a lot is that reading the IEP document itself is just very difficult, seeing a record of all of the ways that their children struggle or are behind. And while I definitely do appreciate that as a parent, from an advocate I think I look at the IEP document a little bit differently in the sense that my personal view is that an IEP document is not supposed to make you feel good about your child. It's not its job to make us feel good and it often doesn't.

And I don't like to get caught up in what it says the deficiencies are. I like to get more focused on what the plan is going forward. And so I just, really in your personal experiences because I know you guys look at these professionally, but you also look at them as moms. And so how do you manage that discomfort for yourself?

Amanda: So a couple of things is number one, your IEP should not just be filled with can't statements. And if it is, that's what Kirby and I call old school IEP. So my son can't wait for five minutes, but he can wait for three minutes, lift the verbiage. Our goal is to get Jackson to wait for five minutes. We are currently at a three minute wait. There is a way to flip it.

I understand how difficult it is when I read property destruction and does not respect others' personal property. That hurts me as a mom because I know that is not how I raise my children but it is part of Jackson having Autism and being a learner at school. So I really focus on although these things are difficult, these are the things that need to be said so that he can receive services. This is your gateway into services. And here's the thing, once the meeting is over you have your big girl cry, you sign the document and you put it away.

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It is the school team's job to manage that every day. That is not your job to manage it every day.

Lisa: I think that's such a great way, it is a gateway to all the services and all the progress that you want to make, I think that's a beautiful way. And also, yeah, it's hard, so have your cry, process that emotion, let it out.

Kirby, how about you? Because you're not just doing this for one kiddo, it's now two kiddos, so tell us about how you managed your own discomfort around reading a document that's not exactly fun to read.

Kirby: Yes, it's definitely hard when you hear the term 'self-injury' and that's your baby. You want to put them in a bubble and protect them. But I know that creating a strong plan is the best way to support my son. And now going through it with a totally different kiddo who has never had anything positive, it's really eye opening. And it does hurt my mama heart a little bit, but at the same time I know I'm there for a purpose. I know I am there to get him the support he needs to succeed. And keeping that mindset during the meeting is what helps me.

And then I do have, like Amanda says, have a nice little cry after, just take your moment, don't even read that document right after. My advice is read it the next day, after you've had your cry, after you've processed this a little bit. Then pick it up before you sign it and reread it. I say, have your moment, let your emotions be valid and then move forward with the plan because you've created a strong plan. That's why you went to that meeting with a plan.

Lisa: Yeah, that's really great. I love that advice and I think that that is the better lens to have going into looking at that document and into that meeting is that this is, again, I think as Amanda said, the gateway, this is the path forward. Well, thank you, both of you so much for your time.

Amanda: Thank you.

Kirby: Thank you.

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