

**Genia:** Welcome to the Good Things in Life, the podcast that helps us support our kids with intellectual disabilities to build good inclusive lives at home, at school and in the community. I'm your host Genia Stephen. Today I'm looking forward to an interesting conversation with Lisa Lightner from the Don't IEP Alone podcast and [adayinourshoes.com](http://adayinourshoes.com). Lisa is a special education advocate and I'm really interested in her opinion about what parents most should focus on or what she thinks are some of the most important things that a parent can focus on when they are thinking about their child's IEP.

**Genia:** Lisa, thank you so much for joining me today. I'm really glad to have you here. And I wonder if you could start by talking about your relationship with people with disabilities and their families and why the Don't IEP Alone podcast.

**Lisa:** Sure. My first child, my oldest child, he's 13 now, but he was born with some pretty significant disabilities. He's one of those kids who is medically complex. And when he was in preschool, his preschool sent home a flyer that I could take a training and become a special education advocate. And so I did that really with no intent of becoming an advocate. I just wanted the training, you know, he was a toddler and I knew enough about the IEP process that I knew that it was complex and that there was a lot to it. So I thought, well, let me take this training. And then to complete the training, I had to do volunteer hours and I just kind of fell in love with it. And I've been there ever since. So I've been serving families ever since.

**Genia:** And what is the, what is a special education advocate?

**Lisa:** Well, I used to work for an agency and it's the same agency where I took the training. And what I did for that agency was I worked one-on-one with students and their parents and helping them get their needs met and helping parents navigate the IEP process. Since then I've left the agency, so I don't do any more of what they call like one-to-one advocacy or individual advocacy where I worked directly with a family. Most of what I do now is online via my blog or my podcast. And I just explained the various concepts and topics to parents to help them better understand the system.

**Genia:** And so in your work as a special education advocate and the work that you do on your blog and the Don't IEP Alone podcast what are you think right now? What do you think right now were some of the most important issues that parents of children with intellectual disabilities should be thinking about?

**Lisa:** One of the things that I really tried to communicate to parents is that only parents, you know, and if you've, if you have a direct advocate working with your family, only parents and advocates tend to look at the outcome and what's going to happen at age 18 or 21 or 25. The way that our school systems are designed is just that everybody looks September to May or September to June, whatever that school calendar might be. And teachers, and I love teachers, they tend to just prepare you for next, you know, they're preparing you for the next grade or the next year or the next school building. Nobody except for parents is really looking at that end goal of yeah, that next what, meaning adulthood. Yeah. Whole life and adulthood. What is that going to look like? And I think that the education community as a whole, you know, we love to look at how many kids

went on to college and how many kids did this. But you know, we still have, at least here in the USA, we have an 80% unemployment rate for people with intellectual disabilities. And to me that's not acceptable. So, so obviously we're not focusing on outcomes.

**Genia:** Right. Or we're not succeeding in what we're doing.

**Lisa:** Right. Right. And that the main thing like, yes, your plan for the right here and now is very important, but you always have to be looking at the end goal and the end result and what that child is going to do or what their life is going to look like as an adult.

**Genia:** Yeah. And it's sort of one of those like don't lose sight of the forest for the trees. And you had a podcast episode, it's not, it's not one of your newer episodes now. Actually it's a while ago, but I can't even remember what you said, but it had something to do with an elephant. Can you talk about that a little bit?

**Lisa:** Right. It's a quote I heard one time. And it's about standing too close to the elephant. And if you just envision that as far as if you're standing too close to the elephant, I think a lot of parents do that and they get too, one of my other advocates who, advocate friends who helps me, she calls it that they just fell in the hole. And it's kind of like you're just standing too close. You're too close to the situation. You've just fell in the hole and you can't get out and see the big picture.

**Genia:** Right. So you're just seeing the wrinkle in the elephant skin as opposed to actually being able to see the whole elephant or the whole being in front of you.

**Lisa:** Right. Exactly.

**Genia:** Yeah. And I think it's really it's too, it's almost to be expected that parents would have that experience because, you know, we, in the preschool years, we're often connected with a medical community and perhaps early childhood development both of which have very immediate sort of focuses, right? Like their goal is not necessarily seeing the whole elephant but you know, making sure whatever the medical concern is it is addressed and early childhood development is very much about those, you know, developmental goals and next step, next step, next step building on it. And they would both the medical establishment to some degree at least some people and certainly early childhood development programs would all say, well, we're doing that because you work towards the next step so that you are working towards a whole life. But that's not necessarily, the next step is not necessarily the whole big picture either. And then we get into the school system and the school's IEPs are by definition, like by the way they're broken down, are very much like specific next step kinds of things and developmental goals with no real attention to the big picture of who this child is and how they might be accessing the good things in life and you know, reaching their full potential and becoming a contributing citizen and all of those kinds of things.

**Lisa:** Correct. And I think the actual full proverb or saying is if you stand too close to the elephant, you can't see the elephant or you don't see the elephant. So yeah, that's just about, that's it. It's about focusing on one small piece of it rather than the big picture.

**Genia:** Yeah. And supposedly if you stand too close to the elephant, you might get stepped on.

**Lisa:** True.

**Genia:** So when you are speaking with parents and wanting to talk, like wanting to bring to this message of not focusing on filling in the gaps, but focusing on the big picture, what are some of the ideas that you encourage people to think about?

**Lisa:** One idea, and this isn't something, you know, I can certainly take credit for. It's an idea I heard many years ago at a conference and that was that she and her daughter had developed a vision statement for the child. And since then, I've always coined the phrase that, you know, your IEP is your roadmap, but your vision statement is the destination. So how do you even create a roadmap if you don't know where you're going?

**Genia:** Yeah.

**Lisa:** And this particular child who's now an adult was already working part time in her community. She had a part time job and was still living at home because she was in high school. And the school was just pushing for sheltered workshop, sheltered workshop, sheltered workshop. And that's where they envisioned this child after high school. And mom wanted supportive, you know, mom and daughter wanted supportive living in the community with a part time job, which she was already halfway there. She had a part time job. So again it was about getting the school on the same page and, and creating that roadmap together. And you just want to make sure that the school is aware of where you want to go. You know, we have to presume competence. A lot of times I don't think it's necessarily malicious. I think it's just that, you know, it's kind of that we've always done it this way or you know, kids with intellectual disabilities, this is what they do after high school. And if you don't push the limits of that and presume competence and create your own vision, someone is going to create it for you. So you want to make sure that it's yours.

**Genia:** Right. Yeah, yeah. For sure. And we actually, Good things in Life has a download on creating your own vision. You can find that a [goodthingsinlife.org/2020](http://goodthingsinlife.org/2020). And yeah, I couldn't agree more. I think it's the, having a clear vision is absolutely essential because just as you just said, if you don't have a vision, somebody else will create one for you and all you have to do is look around to know that that vision sucks.

**Lisa:** Exactly.

**Genia:** Yeah.

**Lisa:** Exactly.

**Genia:** Yeah, for sure. So I imagine that some of what you're talking about becomes really apparent to families if they haven't thought about it previously when kids are transitioning out of high school. So I'm just wondering if you can talk about sort of, I

know that you recommend people kind of reverse engineering thinking about, okay, that may be down the road, but what do I need to be thinking about now? I wonder if you could talk a bit about that.

**Lisa:** Sure. I think when it comes down to it, that you know, any, the sky's the limit. I mean, it really is. The sky's the limit as far as what you want your child to do, what your child wants to do, and what is really available out there to make that happen. But like I said, I don't think that schools are necessarily being malicious. I think it's just that **they get in a rut shoe** of this is what we do and transition looks like this and this is what we put in IEPs at transition time. And it's going to be up to parents to really, again, push the boundaries, ask for more. You're going to have to be creative and most importantly, I think that when it comes to the parent and the child, student, whatever you want to call him you may have to create it. I mean, you may have to go out and make it happen.

**Lisa:** You know, I have a friend who has an adult daughter with disabilities and she went out and made it happen. She went out to, not actually should just go out. It was where she had been taking herself and her daughter to get their haircut for years and years and years. And she went out and approached them and got the training and now the daughter, you know, washes and folds towels and does other tasks behind the scenes of the shop. And it's, you know, a completely appropriate job. She loves being pretty and she loves being made up and she loves having her hair done and she loves just being around all of that, which is a completely appropriate thing for a young woman in her twenties. But it's not something the school would've necessarily offered. So, you know, it was up to the parent to go out and make that happen.

**Genia:** And I know that when we were talking before we started recording this you had talked about social capital as being an important idea and it's directly related to what you're talking about now. And I wonder if you could talk about social capital.

**Lisa:** Sure. Disabled people, but particularly those with intellectual disabilities are at a real disadvantage when it comes to social capital. It's just the way our society has steered them over the years. You know, separate classrooms, separate schools, separate transportation. I don't know what to, I'm sorry. I don't know the system in Canada, but even here in the United States as an adults, we have a completely separate public transportation system for disabled adults. So if you even get to the point where you, your child is skilled enough to navigate public transportation, it will be separate. So our kids grow up in their communities and then they don't know.

**Genia:** Sorry, just one second. Do you mean that somebody with a disability isn't allowed to get on a public bus?

**Lisa:** It's not that they're not allowed but there is a separate system set up for them.

**Genia:** Got you. Okay. I hear you. That makes sense. I just, wait. With your last statement, I was like, "Wait a second [inaudible]."

**Lisa:** They're not forced to use it, but there is a separate system and in fact what I've been told from, from adults who are now using that system is that the, if you want to use that system, you schedule the little bus and all that. You have to give a two hour window ahead of time and you have to give it two hour window at the end. So like literally going to the grocery store could take you about six hours. That's another podcast, I suppose for another day.

**Genia:** Yeah. It's the same. It's the same in Canada. It's the same in Canada. Like the accessible transit system in some major cities is accessible, but in many communities, like my own, yeah. There's a separate system and the system's terrible.

**Lisa:** Right.

**Genia:** Yeah.

**Lisa:** But, so that, our kids grow up in the community, but then they grow up not really knowing anyone in the community. They tend to not participate in sports because they're in segregated athletic leagues and segregated sports. They tend to not participate in things like girl scouts and boy scouts. And if they are, you often see separate troops. So they become adults in the community and no one knows them. And it's just a matter of kind of when your child goes somewhere, it's kind of like norm from cheers. Right. You want everyone to know their name. And that's just something parents are really going to have to work on here in the States.

**Lisa:** We do have many more churches working on being more inclusive and kind of sending the message to their congregations that, you know, what if a child makes noise or whatever during a service, that's okay. Because all these things you know, civic groups, churches, scouts, whatever it is our kids need to be a part of that. Because otherwise, I mean, you really don't expect someone to walk into a workplace at age 25 and say, "Hey, I know you've never met me before, but I was wondering if you could rearrange like your whole facility to accommodate this person to work here."

**Genia:** Right. Yeah.

**Lisa:** So it's kind of getting that buy in and getting that community buy in and we just have to get our kids out in the community. You know, we talk about inclusion and we talk about acceptance but they have to get used to seeing our kids in the community.

**Genia:** Right. People need relationship.

**Lisa:** Right.

**Genia:** Yup. Yeah. And it, what you were just saying around, you know, "I don't know you, but if you could just rearrange everything that would be swell", is a really, like it lends itself towards that old adage that it's not what you know, it's who you know. And that's kind of what social capital is. Social capital is the, it's currency, social currency that comes

with having relationships and being really well connected within the web of your community, not just being in the community but being of the community.

**Lisa:** Exactly.

**Genia:** Hey, I just wanted to jump in here super quick and let you know that if this idea of social capital interests you, then I'd suggest that you go back and check out episode 27 of the podcast with Al Condeluci. You'll find that at [goodthingsinlife.org/027](http://goodthingsinlife.org/027) or you can just scroll back wherever you're subscribed to the podcast. I was also offering a Online Free Live Expert Presentation on the topic of social capital. And that'll happen in March. Registration is not yet open, but keep an eye out for it.

**Genia:** Yeah.

**Lisa:** And it is, I know particularly when you have a child who has a significant amount of health issues too, or it can be more work. You know, if my other son has a basketball game, it's much easier to say, "Well, hey. Why don't you just stay home with Kevin and I'll take Brian to his game." You know, it's a lot of extra work or if it's snowing or pouring down rain to get off the wheelchair and do all that. And I get that because I experienced it personally, but you have to, we just have to push ourselves because again, our community has to get used to seeing these kids out there if we want acceptance and inclusion.

**Genia:** Yeah. And our experience has been that that extra effort really, well, first of all, the effort is not always successful. So, you know, friendships and relationships are, you know, maybe 10 parts planning and coordination and 90% magic. You know, there needs to be opportunities there and there are some things that we can talk about around how we can facilitate and foster the opportunity for friendship and relationship, but essentially there's a bit of a magic component to that. So it's not always successful. But what we've found is that investing the extra effort pays back like any good investment in major dividends over time because eventually when you do have those relationships in those connections, things become an awful lot easier and an awful lot less work.

**Lisa:** It does. Right. There are the barbershop where I take my son, there are two men with intellectual disabilities who help out around the shops - sweep up hair do stuff like that. And just that just their presence, you know, they're helpful in the shop. Of course, you know, they work, but just the fact that so many men come into that barbershop day after day after day and see these guys, you know, it just, it also, it's a little bit of protection for them. You know, if you, someone's not going to be as easily be as able to take advantage of these folks because they are members of the community. You know, the men who go to that barbershop are used to seeing them all the time and look out for them.

**Genia:** Yeah, yeah. That's an excellent example of how relationship protects us. You know, that people look out for us and they notice when we're missing.

**Lisa:** Exactly.

**Genia:** Yeah. Yeah. Yeah. Which I've always found to be a really great question to figure out whether or not like true inclusion and belonging is happening is the question of does anybody miss them when they're not there? You know, and if the answer is no, nobody notices, then inclusion and belonging probably weren't actually happening in the first place.

**Lisa:** Exactly.

**Genia:** Yeah. So how do you incorporate then what we've been talking about today into your work around IEP?

**Lisa:** Again, I don't, sorry, I keep, I hate to keep saying this. I don't know the Canadian regs, but the American regs as far as IEPs are very clear in that IEPs are not just for academic needs, they are for functional, recreational, social, all that. So it is completely appropriate to have goals in these areas and have the kids work towards those goals and have strategies, you know, to support that. I think it's also important, and I'm sure you've probably said this on a podcast before, but you know, that to remember the inclusion means contribution. And just sitting somewhere doesn't necessarily mean that they're being included. Like you said, if someone wouldn't notice the next day that they weren't sitting there, then they're not fully being included. And I think that that's some, that's, that can be a way or maybe a barometer for parents to look for on their IEP as far as how you can have a goal and you can have strategies, but how engaged is the child going to be. It's not just about being present, but they have to be engaged. They have to be contributing something.

**Genia:** As a and that contribution then helps to foster and grow social capital. That's, is that the sort of, yeah. Okay. I see. I understand.

**Lisa:** You know, my high school, my kids aren't in high school yet, but we go to the homecoming games. And one of my proudest moments is that there are a couple of girls with Down syndrome on our high school cheerleading squad. And that just makes me really proud because they're on the squad participating with all the other kids because you know, we all see what gets passed around on Facebook with these all Down syndrome cheerleading squads. And I think, okay, that's cute, but why, why can't they be on the regular squad? And the truth is there's no reason why they can't, but they are, they're building relationships. I know on the parents of some of these girls, I know they get invited to sleepovers and they get to do all the normal things that teenage girls get to do.

**Genia:** Right. Yeah. Excellent. So Lisa, if you had sort of one parting message for parents of kids that are contemplating their next IEP review or anything in particular, you know, that we haven't covered today, do you have any last advice or suggestions for people?

**Lisa:** Do you mean just with, you know, I know you're podcasts tends to focus mostly on intellectual disabilities. You mean that or overall?

**Genia:** Yeah. Whatever you think is going to be most important for people to hear.

**Lisa:** I think most of us would give, you know, our right arm or left arm to never have to go to an IEP meeting again, to not have to do all this.

**Genia:** We're just telling parents secrets here, Lisa.

**Lisa:** I always say it's the knowledge base I wish I didn't have to have because they are, they're stressful, they're time consuming. You know, they're not fun.

**Genia:** Yeah. No.

**Lisa:** But I look at it as, you know, whatever you're going to do, do it well. And these are the cards that we've been dealt so engage the whole year round not just at IEP meeting time. Engage all the year round, you know, keep checking your child's progress. Don't wait until the day before the meeting and look at last year's and go, oh, how much progress have they made. Because if they haven't made progress by then, it's too late. You've lost a year. And just staying engaged the entire year round. You know, you don't want your IEP team to only think about your child's IEP once a year, so neither should you. And I just, it's very frustrating as an advocate because there is a lot of that that I get from parents that "Hey, my IEP meeting's next week" kind of thing. And a lot of parents do only think about it, you know, say once a year and the rest of the year they just kind of go with the flow and assume that things are going well and that things are being followed and stuff's getting done. And that may not always be the case. So stay engaged all the time.

**Genia:** Great. Thank you for that. Lisa, if people want to connect with you, how would they find you?

**Lisa:** Sure. My website is called [adayinourshoes.com](http://adayinourshoes.com). As you said, my podcast is called Don't IEP Alone and you can find that everywhere. It's on iTunes, it's on Stitcher, it's on Google play. Pretty much anywhere you can find a podcast, it is listed there. And those are the two main sites. If you want to search either of those, there's a Facebook group, there's a Facebook page, all that fun stuff.

**Genia:** Wonderful. And we'll put links to that to those in the show notes. Lisa, thank you very much for joining me today. I really appreciate it and I look forward to staying connected.

**Lisa:** Thank you. That was fun.

**Genia:** Thanks so much for joining us today. If you are interested in developing a vision for the life of your daughter or son with an intellectual disability so that others don't develop one for you, that frankly sucks, then you can download the guide to creating a vision that I've created called Setting Goals That Matter. And you can find that again at [goodthingsinlife.org/2020](http://goodthingsinlife.org/2020). I look forward to speaking with you next week. Take care.