



**Episode #184:**

**Wendy Besmann on Navigating  
Health, Education, and Insurance Systems**

November 19, 2019

Debbie: Hello Wendy, welcome to the podcast.

Wendy: Hello Debbie. Thank you for having me.

Debbie: Well, I would love as a way to start, you sent me a lovely email giving me a little bit more about your story. Would you mind sharing for my listeners some of your, your personal experience that inspired the work that you do in the world?

Wendy: Sure. Get There Project evolved out of my experience as the parent of two wildly differently wired children, Elliot and David, who are grown now and independent. Hallelujah. I'm thrilled to say, didn't think it was going to happen sometimes. But it evolved out of my having to go around and find the services and supports they need. I mean we all know that diagnoses are pretty much for school system services and insurance coverage, but lots of labels flowed through our household, ADHD and giftedness and sensory processing disorder for Elliot and autism and bipolar disorder for David and I was wandering through the wilderness as so many of us do, trying to find services that fit the kid and it's such an overwhelming process. It is like moving into a strange new world where everybody speaks a different language and they have all kinds of rules and customs that seem very bizarre and you have to find your way through.

So in the course of doing all of that, I began to collect strategies from other parents because I didn't know what to do. And I had these children who did things that were really hard to understand. My younger child David was kind of a wild man who got bounced out of four preschools by the time he was five because between the autism and the cycles of the bipolar disorder, he tended to scratch, kick and bite whenever he got upset and was disinvited from a lot of places. And the school system spent a lot of time trying to figure out what to do with David, whereas for Elliot it was a lot more of a thing that could get missed because they just didn't know what to do. I just heard this is a very, very bright person who we don't know how to deal with because there's no respect for authority because there's all this impulsivity. And on and on and on. And also these sensory processing issues, which everything was too hot, too cold, too rough, too uncomfortable.

So trying to figure out how to support these children became this process of trying to figure out how to navigate systems to get what we needed. Because when we have differently wired children, the services usually don't fit really well. And I feel like the typical parent thing is you call up and you say, what I really need is A, B, and C, and they say, well, we don't have A, B and C, we specialize in D, E and F. Go down the street here for A, B, and C. And you go down the street and you stand in line and you get there and they say, what kind of idiot told you we had A, B, and C, we really have X, Y, and Z, and that's what you really need. So

fill out this form and get on the waiting list and in three months we'll call you. And that's kind of your life when we're doing this. So that's why I started to collect strategies about what worked for other parents. And it became the first workbook that with other family advocates evolved into the roadmap series and the guiding star.

Debbie: So how did you, I mean I feel like everyone listening is like, yes and like I can completely relate to your story 'cause I hear from so many parents, you know, just the, especially the school like just trying to figure that out. And you know, that was a big reason why I started Tilt as well was just this idea that you just don't know where to start and it's hard to gather that information. So how, I'm just curious how you went about, you said you talked with other parents, but could you share a little bit more about your curation or your research process?

Wendy: We'd all started with a pilot program in the state of Tennessee where I live part time and it was all about what families did that worked. Because I had a lot of interaction with families through nonprofit work, through advocacy, through National Alliance on Mental Illness, various things. And so we came together with some of these families and also organizations that served families, family advocacy organizations, mental health agencies, insurance carriers, and put them all together in an advisory board. I know I thought like, you know, I couldn't believe they were willing to actually do this 'cause I was just this mom sitting over here. But I, I got everybody together in a room and we decided to create this workbook, getting 20 different psychologists, psychiatrists, insurance carriers and whatever to work on something together was a nightmare. But eventually out came this book and then it became a nationally distributed book and then a number of family advocates started using it around the country and they said turn it into a curriculum.

So we did. And eventually they came together to help create this roadmap series. It's sort of built and built and built so that now there's a certification program for using the roadmap curricula and workshops, coaching and now e-learning, we are so excited because families more and more like to go online to get their learning. So it has been this wild ride. Just going from here I am wandering through the wilderness, trying to figure out what's right for my child after I get the phone call, Elliot's getting kicked out of band because of getting bored and chewing on the plastic band chairs and I go, what? And then on and on and on, because this child had some very wacky behavior and David had some very aggressive behavior. So I'm always getting that come and get 'em phone call. You know what that is? Or what a friend of mine calls the cold, wet slap in the face where you feel like, you know, everything's going fine, rah, we're doing the right thing and then, whoops, you get this phone call and it all falls apart.

So it's been a process of coming together with a lot of people who share that same experience to put together these materials that could be used. And another thrilling thing is that this process is now used, this guiding star process in our roadmap series is used from Maine to Guam. A couple of months ago we trained family advocates in Guam to use this process. So that was enormous and it really made me feel good about using this kind of a process because what we're going for is to somehow keep it very simple, a simple five step thing you can do

wherever you go. Because my experience was as we navigate systems, it's not just one system. The problems change, the programs change, the procedures change, the personnel changes. But this guiding star process, the five steps of what you have to do to break up a messy problem is like the North star, it doesn't change. And the reason is that people and systems are very predictable and you can navigate using sort of an all purpose tool because mostly when it comes right down to it, you're interacting with people and there are some basic rules of the road that make that easier.

Debbie: So, okay, I want to get in more to the details of the guiding star process, but can we take it a step back? I want to make sure that listeners have context for exactly, you know, how this would, would help them or what situations they would apply this process to. So you mentioned systems that, you know, is this something that a parent would tap into to navigate, you know, everything from figuring out a path for a child's education to getting insurance to dealing with an afterschool program that doesn't quite get it to, you know, I guess give us some context for this work.

Wendy: Well it works for just about anything because if you are in an IEP meeting, if you are on the phone with a customer service agent who does not want to give you insurance coverage for a therapy, if you are dealing with any other type of problem like this, it's all the same thing. So I mean I personally logged a hundred IEP meetings with, for my son David and it worked every time because the whole principle is whatever it is, wherever you're, you're trying to find, you're pretty much starting with a big messy situation. You're pretty much starting with, I don't even know where to start. And we say that knowing where to start makes all the difference so that you can say, okay, the first thing I need to know, whatever it is, because the school system is not getting it and we're not getting what we need and my kid is crashing and burning.

You need to know what do we need most right now and have a process for getting to what you need most. So they're not saying A, B, C, D, E, F and you've got to go, ooh, whatever. What do I need most right now? And that is based on your child's true strengths and your family's strengths, but also figuring out what your priority concerns are. And it may not be what you think. And then when you've got those goals set, you have to go into a system and learn the basics of it because every system is different. It has its own language, it has its own procedures, and you've got to make yourself smart about that. And then you have to, no matter what kind of service you have, whether you are looking for insurance coverage or you're looking for that gatekeeper in the school system who is going to help you, you have to build relationships with those people so they help you get what you want and what your child needs. And then you have to learn how to manage information because tremendous amount of data and paperwork and percentile scores and whatever are coming your way. And you have to learn how to corral that, manage it and make it usable for you. And then finally you have to learn how to find support because one thing we all know is these problems keep happening and happening. I am here to tell you it doesn't even stop when they turn 18, definitely.

Debbie: We don't want to hear that, Wendy. Please.

Wendy: But it gets better. It gets a lot better. But no matter what, you have to have the support, have the resources to keep you going when it happens. So really set goals, learn the system basics, build the relationships, manage the information and find support are these five points and wherever you go it will be better and easier if you use them. They're not rocket science, they're just, it's just a system.

Debbie: It's a system. It's a blueprint. Which you know, again, when you're, when you don't know where to start is really helpful. So I'm wondering if you could kind of walk us through an example of a messy situation. I'm just thinking right now is the time of year, as we're recording this it's, you know, mid October, this is a time I know sometimes things, problems start to arise at school. We might be realizing that, you know, maybe the IEP that we have in place, we're starting to see some flaws in the plan and we need to address them because we're noticing our child is not thriving in school or there's been disruptive behavior or whatever's going on. So could you, using that scenario as an example, walk us through how this five step process would help a parent navigate that.

Wendy: Well, one of the things that would help first is knowing you've got a process because it often seems like such a blur, but you just start from the beginning every time. And I should say that in my case, a cyclone hit my backyard, took out the deck, uprooted trees, and I used this same process and it got better, so it does not matter. It will work. But the first thing you do as you're walking into that meeting is you know your role. And what often happens is you're going in and talking to a lot of people who have got a badge with a job title and a job description behind that and a thing they need you to do. Sign this paper, pay this premium, whatever it is. They know exactly what they're after, but you walking into this situation don't necessarily know that. You haven't got the badge and the job title and the job description. You're the parent.

So first is to know what is my role in this interaction that I'm going to do because it's all about the interaction. My role when I'm walking into the IEP meeting is based on what my goal is and how do I set those goals. The first thing would be to figure out what I really need out of this situation. When you're going in there, what is the true problem? What are we really trying to solve? And that comes from going, hmm, what are our very deep strengths? We have a method for drilling down beyond the surface to come up with your true strengths that can be used to create solutions in this situation of behaviors or the IEP is not working. So what have I got that I can bring to the table from my child, from myself, from my family, and what are my priority concerns?

I personally have all kinds of things I might worry about at three in the morning. The biggest of which, what's going to happen when my child grows up? You know, that's always there. But right now, walking into this meeting what do I need most, and that's number one. That's the first point. There's a process for doing that. And then as you're walking in there, you know what you're there to accomplish and therefore you can say, here is a problem that needs to be solved. Frequently I have actually put an agenda on that IEP table to say, here are some things I think we need to address because I believe a lot of it is about coming into your own power and not letting the other end of the interaction have the power

over you. So there are a lot of strategies for doing that involving where you sit at the table and who you make eye contact with and whatever.

But the basic thing is to know what you're there to accomplish and when you do, you can not make it emotionally neutral cause I'm never going to be emotionally neutral, but you can make it shared ownership of this problem. Here is a problem that I see happening, here is an issue that's coming up and we all go mmhmm, mmhmm. We all agree on that. Well what are we going to do about it? Here are some things we can do. How do you feel about this? What else would you suggest? There, that problem is on the table inviting everybody to take impersonal ownership of the problem. And I find that that interpersonal approach really makes people get on board to help my child. So that's the first thing. Knowing your role when you walk in that meeting and knowing what that, how that system works, and having skills to use that system. And then knowing who your allies are or knowing how to make more allies, knowing how to listen to test scores, that information thing.

And who else can I bring in that's gonna support me. So in every situation I've gone to, I have basically worked through those numbers. And recently this happened to me in another setting some of your listeners with older children might be familiar with and if you don't, hey, it's in your future, is vocational rehabilitation. Which is a terrible system basically, very complicated. And I was in a meeting trying to work on how to get my child a job. And it was all a blur. It was just words on paper. It was nothing. And I thought, wait a minute, you've got a system, one, two, three, four, five. And I started with what do I need most out of this situation based on the strengths we're bringing to the table and my priority concerns and the fog kind of dispersed and I could go on.

Debbie: Hmm. So it's kind of taking, you know, we can't get rid of the underlying emotions or fears or concerns, but it's such a rational approach to things that it helps us kind of stay more in our head. Right?

Wendy: Yeah. And it helps you know that I'm bringing a lot of emotion here, but what I'm doing is that I'm inviting other people in the most neutral way to help me take ownership of the problem. I've walked into the room and I've, my record is having 15 people at that table at school and just me walking in the room and they made me cry once, but only once. Because as you walk in that room, it's your problem. It's your problem with your child who has a problem. They're right. You're wrong. Just because you've walked into the room. And what you're doing is shifting that power interaction so that everybody is invited to look at this situation and come up with creative solutions. And that's one of the reasons why you dig down and really look for those strengths. Because those strengths your child has and that you and your family have plus the supports that those various institutions, the schools, the insurance, whatever have, those are where the solutions come from.

Debbie: I'm wondering if you have any tips for the second step in this process about learning you know, the system basics because I think, I know for me personally, that's where I've always gotten hung up is almost just a sense of just overwhelm. Like you know, where do I even start to find this information? Or maybe I just

kind of shut down because it just seems too tricky to figure out how to navigate the insurance reimbursement for therapy or whatever it is. Like do you have any strategies or hacks for helping parents know how to dig into that information or discover it?

Wendy: Well, a lot of specific strategies that you uncover when you start to get into these systems, but the basics are to realize that they really are alike in certain ways. Because every system you go into, insurance, school system, whatever, it is really like going to another country, they speak a certain language to one another in order to exchange information. They use words and those words are often unfamiliar and you don't need to learn all the words, but you need to learn how to, you know, ask for coffee. You know, you need to learn the most basic words and we call them keywords. Keywords in any system that can really open doors. For example, a keyword in the school system and in health systems is, keywords, they're actually two words, medically necessary. Medically necessary are keywords that open doors and you learn in that system what those words mean and the power that those words have.

So you have to go in there and just say, hmm, what are the most basic words that you need to learn? And in the back of our book we actually have a glossary, a rather long glossary of all of the keywords that are in different systems that are very helpful to know. So that's the basics. Learn the language. And once you do that you are way far ahead because you can get on the phone with the insurance company I think is kind of the ultimate and say I'm looking for X, Y, Z and you can talk the talk and then they know what to do with you. And one of my little tricks for insurance companies is when things are getting real complicated, you ask for a field care specialist, in my insurance system, it may work elsewhere differently. But you ask for the person whose whole job is to solve problems for people because the person that you first talk to you on the phone, their job is to give you information, to process information.

They're at a real low level, but there's somebody behind them whose job it is to deal with problems and you want to get to that person. And here in America it is often the person with two names. They have a first name and a last name and a phone number, you can call them back. As opposed to just call the main number on the back of your insurance card and explain the situation and you're having to explain it over and over. If you can ask to speak to a supervisor and ask to speak to a supervisor and eventually get to this person who has two names, it's gold. Try it.

Debbie: That's so funny. We're looking for people full, fully fleshed out humans with two names who exist and that we can connect with again. Right.

Wendy: Exactly. And one of the other sort of handy dandy little tricks that work in every system is to walk into any appointment in the school system or any other appointment, works like a charm in doctor's appointments, and come with a numbered list. A list where you can pull it out of your pocket or your purse and say, I just have a few questions, comments, whatever, number one. And you start running through this. Must be written down. That's how the magic works. And it is like a response that you get from people in professional capacities that they

will think, they may have their clipboard and be headed out the door, they will slow down, they will sit down and they will listen to you because you have organized their world with a numbered list. And I've had people try this in a lot of different settings and it's kind of magic.

Debbie: Very interesting. So I'm wondering who you know, you typically work with at the Get There Project. So I'm recognizing that this is support for families and parents, but do you also have, I don't know, is this like ever a two way street in terms of getting teachers and educators for example, on board and so that they're, they can better show up to these types of situations? Or are you really giving the strategies for parents specifically?

Wendy: That's an excellent question. We have actually worked more from the end of agencies, schools, mental health centers and things like that because that's been a way that we could get to families. And actually some of these agencies and centers, this is how I started, they buy the book by the hundreds to give out and they wanted some way to coach families and work with families. So in our training sessions, frequently the people we have are education administrators or teachers or people who work in mental health agencies, often people who work in peer support capacities as advocates in mental health agencies, developmental disability agencies and so on. So we've worked with people all over the country and we actually have master trainers that are certified to go out and teach this system within their own communities in that way because working through these agencies, I think is more of a wraparound way then, it shouldn't all be on us. They should have their brains adjusted too.

Debbie: Yeah, absolutely. Because I mean many of these agencies exist specifically to deal with our families. So how great would it be for us all to be communicating and using the same language and having, working towards the same goals instead of, I think so many of these relationships have this inherent adversarial tone to them and it seems like that it really shouldn't be that way.

Wendy: It should be that way and it needs to be that way because once you start getting into the adversarial tone and believe me, I have gotten irritated, then you are not getting something accomplished because you are not getting other people to step up and take ownership equally in the problem and you're not dealing as an equal. So, I always like to talk about the, my children actually call me on this, it's called the thin edge of annoyance that gets results in your voice. Where you are being very, very sympathetic about people's frailties and problems but you are being very firm about the results that you need to get. And it is a two way street. It invites everybody to take responsibility, but it often falls to us to find those people who are really open to doing that. And they're out there. They want to help.

Debbie: Yeah. I'm wondering if you have any, I'm trying to get all your tips and strategies, you know, I think too, one of the pieces of this is the overwhelm, just with the information. You know, I remember at one point, I think I had an organizational expert on the podcast and I was just talking about how overwhelmed I can get with all the different assessments and reports and, and she's like, why don't you make a binder with all the materials that you're asked for over and over again?

So you know where, and I was like, okay, that's a great idea. So I've got a binder now, which felt like rocket science to me, like making that connection. But, so I'm wondering, do you have any, because you're talking about creating systems and having a path when we're out in the wilderness, like do you have any strategies or advice for organizing the material, whether it's insurance companies or school things or education, whatever it might be.

Wendy: There's so much of it, isn't there, and it just never stops coming. And I personally, I don't like to take advice from neat people because they have these elaborate systems that make sense in their heads, but I am actually a messy person by nature who kind of throws the paper. You know I use a binder too but I tend to kind of like throw the papers into the binder and sort it out later. And my philosophy is number one you have to know how you think. I mean here we are dealing with our differently wired kids trying to retrofit their worlds to work with how they think. Well we've got to think about how we think also. I think messy. So I need a system that does not involve a great deal of maintenance for me. That lets me just figure out what do I need right now and when I'm done, well I'm going to give myself a little time to neaten it up later.

I also like to say the three ring binder at least keeps it all in one spot. I like to keep a spiral notebook so that when I'm talking on the phone I can jot down things like the time of day and who I talked to and what their badge number is and so on, which I've had to use as a chronology to get insurance coverage when it comes to the wall and they don't want to give it to you. But the main thing is number one, know there is a way to manage the information because it's not all important. And the other is to have something that works with your head to contain all this information so you feel in control, not somebody else's system but yours. And when you think about it, it really makes it easier because in fact we're doing this for our kids already.

We don't give ourselves enough room. There are some specific strategies for that, that have to do with not only being able to organize paperwork, which is what we always think of in terms of managing information, but also in the way we receive information from other people. We have a strategy called how to listen to test scores because you know they're, they're standing there, they're talking to you, they're showing you a piece of paper and it has all these numbers on it. And I tend to fuzz out because they're going blah, blah, blah, blah, blah, blah, blah, blah, percentile percentile and usually means your kid is tanking, is what it usually means. But there is a way to question people interactively so that they tell it to you in a way that makes sense. So that they interpret what they're saying in a way that actually communicates to you. And there's a way to do that by you asking questions. And so we have to think not only in terms of what we are, in our binder, the fact that we never, never, never let loose of those original documents and we take them back whenever we leave a meeting and this is just the procedure, but also in the way that we are listening to and processing information.

Debbie: Super interesting. So can you as a way to kind of wrap up our conversation, just tell us a little bit more about the Get There project and what parents could find as resources within your organization?

- Wendy: Well if they go to our website, [getthereproject.org](http://getthereproject.org) you'll find a number of resources not only for parents but also for educators, for people in agencies and for people who are supporting and helping young adults. Because one thing I didn't mention is that there is a whole program for young adults who have to start in their teens and twenties navigating the world on their own. And this is something I speak about a lot and I was really thrilled that in one of the speeches I gave recently, there was a woman with a nine year old child in the audience because she was starting that soon to think about the big picture of what her child's life could be if she was planning. Just starting to think about it and it's really worthwhile. But if they go on the site, they will find a number of resources, sharing strategies, things that they can just use immediately. And also portals to get to things like the family roadmap, the young adult roadmap, workbooks, opportunities for coaching, for being trained as coaches and ways to use our new elearn interactive e-learning courses, which you can just do online by yourself. So various resources and they're all there on [getthereproject.org](http://getthereproject.org).
- Debbie: Fantastic. So listeners, I'll have links in the show notes page if you want to check that out. And it's just such an interesting conversation and I, when you reached out to me, I was so curious to learn more. I, first of all, I love talking with people who, whose personal experience and passion drove them to, I don't know if drove is the right word, but inspired the work that they're doing in the world now and, and who, you know, people who create what they needed. And it sounds like you certainly did that and so many helpful resources for families. So thank you so much for taking the time to come by and share with us today.
- Wendy: Thank you for talking with me.

## RESOURCES MENTIONED:

- [Get There Project](#)
- [Get There Project on Facebook](#)
- [Get There Project on Instagram](#)
- [Guides and solutions for families](#)
- [Sharing Strategies resource on Get There Project](#)