HPAW Eric Jorgensen

**Doug Foresta:** Welcome to Human Potential At Work, the show where we explore social impact, inclusion and empowerment of everyone, including persons with disabilities. Your host is Debra Ruh, CEO of Ruh Global Impact and co-founder and chairwoman of Billion Strong. An identity and empowerment organization designed to bring billions of voices of persons with disabilities together.

To join the global community and to donate to the cause visit billion-strong.org. That's billion-strong.org. And now onto the episode.

**Debra ruh:** Hello everyone. My name is Debra Ruh and I'm the CEO of Ruh Global Impact. And we work with clients all over the world, making sure they're meaningfully including people with disabilities as customers and employees. I'm also the executive chair of Billion-Strong. So my guest today is somebody that I actually needed when my daughter was younger.

Um, it is Eric Jorgensen and he is the CEO and founder of TrueNorthDisabilityPlanning.com and he considers himself a Special Needs Navigator, which is a common, we hear the word navigator with special needs often in the United States. And goodness knows we need that. Um, because our systems are very, very complicated and most of our families, we just really don't know all the rules and they shift and change too fast. So I know that Eric has his own podcast and he talks about these things a lot and I was seeing his work and I just loved what he was doing. So I wanted to have him on the show today. So let me do a quick visual description. I am a mature woman with, um, Gray and white and purple hair.

And I have on a black dress today with purple glasses. And of course I have some bling all around my face cuz with my eye glass holder cuz I love bling. So Eric, welcome to the program. Tell us about how much bling you've got going on.

**Eric Jorgensen:** Thank you Debra. I can't say I have any bling.

I am a, I'm gonna use your word, mature, caucasian male with brown glasses, brown hair. What little I have left it, it tends to be receding as I get older, I'm wearing a rather plain maroon shirt.

**Debra ruh:** Great description, but no bling all right.

**Eric Jorgensen:** No bling.

**Debra ruh:** So, so Eric, tell us about, you know, get, tell us about how you got into this.

How did this start? And also, I know you're gonna explain to us what a Special Needs Navigator is. So tell us. You know, tell us your story. You have a, a powerful story, sometimes sad, but also sometimes good. Right?

**Eric Jorgensen:** Absolutely. Thank you. And Debra, thank you for having me. Um, I think my story is similar to many of, many of those who work in the disability space in that I'm coming to it from personal experience.

The, prior to prior to starting Special Needs Navigator now, True North Disability Planning. I was in the Navy. I did 20 years in the Navy and I was retiring in 2012. I was supposed to retire in June and my wife got a sudden illness, spent a week in the ICU and they took her off life support in April. So I ended up extending till December.

And, uh, you know, I know you've shared, you recently lost your husband. And so I. I'm very confident, you know, just how much of a, it takes the wind out of your sails and you were married much longer than I was. So, um, yeah, it sucks.

**Debra ruh:** It hurts.

Yeah. And, and then you have your special needs children too still.

Yeah, so.

**Eric Jorgensen:** Right. Yeah. My, my son is on the spectrum. Um, you know, he's got some other challenges. And, you know, he was 12 when my wife died and while she was alive, she would be her, his full-time caregiver. She didn't work. He was, you know, he would go to school, but when he wasn't in school, she was doing everything, helping him out.

And when I would come home, I was deployed a lot and I was, I was a geographic bachelor's, meaning I would live. I lived in Cuba for two years, lived in Virginia for three years, my wife in, somewhere in Connecticut. So I'd come home every, you know, three or four months for two weeks and pretty much just stay out of her way.

Because if, if I, you know, you have a routine and you, you don't need somebody else getting in there and messing it up. And I didn't really know much about what it meant to be a caregiver. I never cons and I still don't consider myself much of a caregiver. And so as I'm trying to get my son situated and I'm trying to get out of the Navy, find a job and figure out what's going on.

I just, I wanted somebody to make it easy for me in regards to what I need to do for my son. What am I supposed to be doing? He's transitioning to high school. What comes after high school? What am I not thinking about? What questions am I supposed to be asking that I'm not asking? But there's nobody at the time.

I couldn't find anybody that would do that for me. So.

**Debra ruh:** Which is still very common, very, it's hard to find. And can I also say that, um, as you, as you just said, walking it, um, you also were in major grief and so was your son. And I know my daughter with down syndrome has been really struggling with trying to wrap her hand, her head around losing her father, which by the way, me too.

Right. So I just wanna add that little piece to it too.

**Eric Jorgensen:** Yeah. It makes for an interesting soup, if you will. Right? I mean, you know, loss of, and there was also a loss of my identity from the Navy, you know, not, you know, there's just, 20 years is a lifetime.

**Debra ruh:** Right, right.

**Eric Jorgensen:** Um, so I'm I'm I joined, I went into financial services.

Because I thought a financial advisor gave advice. I was pretty naive, you know, I didn't know it involved selling. I mean, I think I probably did. I don't want to, you know, put, and I don't wanna take the onus off of me, but it didn't really sink in how much selling was involved and how little advice there was at least in the beginning.

**Debra ruh:** I agree.

**Eric Jorgensen:** Um, and then over the next couple years, I bounced from, from firm to firm because I was trying to find something that was a better fit. I didn't wanna sell insurance. I saw the need for it.

**Debra ruh:** Right.

**Eric Jorgensen:** Um, you know, my wife didn't have enough insurance when she died, so I was renting a house and paying a mortgage in Connecticut, renting a house in Maryland.

And that was, you know, it was all I could do to stay afloat. So I definitely saw the need for insurance, but it wasn't, it wasn't scratching the itch of families need help.

**Debra ruh:** Yes.

**Eric Jorgensen:** Especially families that don't have a lot of means um, you know, and so I would bounce from financial firm to financial firm until 2020 came.

And then I, um, I had had, you know, one more thing. I had cancer where they, they cut off the left side of my face because I had an aggressive melanoma. So...

**Debra ruh:** Wow!

**Eric Jorgensen:** Yeah, you can't see it, but if you can draw a line from the bottom of your ear, to the bottom of your lip, you know, of your lip on the left hand side, and then, you know, just draw an imaginary line underneath, along your face, underneath your eyelid, down your nose.

And just that, you know, like I said, it literally removed the left side of my face.

**Debra ruh:** Wow.

**Eric Jorgensen:** Um, so as I was recovering from that, Uh, you know, and this was in March of 2020, right when COVID was starting.

**Debra ruh:** Oh, good.

**Eric Jorgensen:** Um, you know, I'm, I'm like, well, you know, I'm, I'm tired of being square peg round hole. I'm just, I'm tired of, and it wasn't fair to the companies I was working with candidly, because I have this vision of what I wanna do to serve the families with disabilities.

And I really wanted to focus on intellectual development disabilities. I, I didn't wanna do financial planning. I knew there was something else that needed to be done. Nobody was talking about benefits, resources, and services and, and how to navigate that maze. Um, and, and so I decided as one does in the middle of a pandemic, let's start a busines.

**Debra ruh:** How hard could it be?

**Eric Jorgensen:** Right!

And that's when I launched. And, and I really incorporate, I had, I started Special Needs Navigator in 2017 as kind of a hobby if you will. Um, because I wanted to give the advice, but I couldn't really do it under the auspice of a financial advisor or at least I didn't feel I could because it wasn't financial advice.

So I started Special Needs Navigator to give that advice. And then I rebranded this year because I felt, I, I never say, and this could just be me, but I never see my son has special needs. I always, I'm always very clear about his diagnosis.

**Debra ruh:** Right, I agree.

**Eric Jorgensen:** Or, you know, he just needs his assistance and I've gotten, uh, I've seen, I haven't gotten a lot of personal pushback, but I've seen in the, in the, a lot of the social media in the press, that special needs, isn't really how people wanna be identified.

**Debra ruh:** I I've heard that as well. I agree.

**Eric Jorgensen:** So I've rebranded to True North Disability Planning. Cause I wanna be respectful of that. You know, ultimately I'm doing this to help families and professionals, um, and, and I've really doubled down on: if you have a child with, with moderate to severe, who's moderately to severely impacted by your, by their disability.

Meaning, you're probably gonna care for them for the rest of your life. You need somebody in your corner who's doing more than just saying, this is how much you need for retirement. Which is important, but...

**Debra ruh:** I agree, but there's so many other steps and there's special needs trust, and, oh, it's so confusing.

**Eric Jorgensen:** And how do you decide what to do first and where do you go and yeah.

**Debra ruh:** And do it right. You better do it right. Don't you mess up Sara, you know, it's, it's nerve wracking and everybody I know is scared of it. And Eric, are, are you looking at it across the United States or just state? Because I know every one of our states had different laws. Every one of our counties in our states have different laws just to confuse us all completely.

**Eric Jorgensen:** Right. And,

**Debra ruh:** and yeah, I'm, I wasn't sure.

Yeah.

**Eric Jorgensen:** That, it's a great question, Debra. And, and it started off in Maryland because I was being very selfish and I wanted to help my son. And my overinflated sense of justice took hold. And I was like, why is this so hard? Maybe it's easier in other states. It's not.

**Debra ruh:** No it's not.

**Eric Jorgensen:** Um, so that turned into, I went through all 50 states and DC and I've mapped out. I've created literal, literally created roadmaps for what you need to do to transition your child from high school, into adult services.

**Debra ruh:** Wow.

**Eric Jorgensen:** And you know, and I've built them. But it took years, literally took years, but it was like, it, it.

It's that thing that took a hold of me and I'm like, this can't re I, I just cannot, once you've seen it, you can't ignore it. Right. Like if you're doing a bathroom and you, you, you take the shower out and you see mold, you're not putting a new shower in until you get rid of the mold. Right.

**Debra ruh:** Hopefully, because that is a bad idea if you do. Right, right.

**Eric Jorgensen:** Yeah. So I just, it, it just, I decided you know, I am going to fix this and, and I've, it is in my mind, I'm, I've, you know, the disability space has become my windmill and I'm here as Don Quijote, just out there chasing these things.

**Debra ruh:** Oh yeah, I understand.

**Eric Jorgensen:** You know, but it's, it's to your question about the counties, I'm a 30,000 foot view guy, so I'm very good at map, at explaining at a, at a very, um, you know, macro level.

Here's what you need to do at your state.

**Debra ruh:** Okay.

**Eric Jorgensen:** Where I, where I'm not gonna be able to help somebody, and I'm hoping somebody else will come in and take up the manual is if I live in Michigan and I'm trying to find an agency for, you know, pick a city in Michigan in, in what agency should I be using? Well, I, I can't help there.

I, I don't know. I mean, there's so much for me. I, I literally spend hours every day at the state Le you know, at the, at the macro level, I'm really hoping that, and there may be people out there already doing it really out there doing that at the state level saying, let me help you. You know, I know there's one company.

If I can give them a plug, uh, Vital Exchange is a company that has vital guides and they're, they're offering, you know, parent and peer navigators who will, uh, I believe it's at a state level. You hire Vital Exchange and you, you can set up time with these, with these. Vital guides to get, to get assistance.

And I don't know how much, I don't know too much of their business model, but I know they do cover things like IEPs and, and services. So.

**Debra ruh:** Okay.

And IEPs, which are individual educational plans here in the United States. And, um, they're very, very complicated too. They're very, very complicated. And I remember I would go into my daughter's IEP meetings and.

There is just, boy, you better be prepared. And most of us are not prepared. E and even the people sitting in those meetings with you, they don't know what they're doing either. And I don't mean that in a nasty, negative way. It's just. There's just too much to know. And we, we put such burdens on our teachers to know everything and they just can't, they can't know everything.

And so even our special needs teacher. So it's, it's a huge, huge step and mess. Well, I would be curious. Um, how do customers work with you? How did they find you, Eric?

**Eric Jorgensen:** Um, a lot of 'em will find me through my podcast ABC's of disability planning. My YouTube channel by the same name of my company, True North Disability Planning.

And I get a lot of referrals from professionals, financial advisors, college living experience, you know, disability professionals are, are referring to me. And with regards to how they work with me, I, I really have, uh, three paths, you know, two, two for professionals were I offer I'm I'm I've branded something that I called the chief navigation officer.

I believe every company is going, that is serving individuals with disability is going to need somebody in that company to help them navigate the maze of benefits, resources, and services. Just like you have a chief financial officer help you with the finances. You have a chief, chief operations officer, who's helping with the day to day operation of the company.

So right now I'm offering professionals who serve the disability space again, specifically intellectual development disabilities. I'll be your fractional chief navigation officer. So you don't need a full time person and you don't have to try to fill this role right now. So that's one way. I'm also offering professionals the opportunity to white label a lot of my roadmaps, because I recognize they're doing amazing work. And a lot of times they just need that extra tool or two to help them with their clients. So here you go. Use my, use my content, and then with the families, I will, um, they can either buy the roadmaps from my website. You know, again, I've, I've tried to make it accessible by keeping the price, you know, reasonable.

Or they can hire me for consults. And I have a pick my brain, which is, you know, literally you've you have questions. I have answers. I'm not gonna do a ton of research or anything like that, but it's, it's gonna be an opportunity for you to get your questions answered. I have, an 'I don't know, I don't know', package, which, you know, I, I did it all with how I felt, right.

I wish I could pick somebody's brain. I didn't know what, I didn't know when my son was transitioning from high school, so right. That I don't know. I don't know. Package is meant to help you get from high school and adult services and then..

**Debra ruh:** Which is, which is such a hard, of all of the steps we took. That was the hardest transition.

And. Failure failures, transition failures all over. And you know, and it's a very sad statement that many, many, um, people who have special needs or disabled children say is that I hope I, I outlive my child. That's not something we say in society, and yet we are terrified of what's gonna happen. I have a 35 year old with down syndrome.

I mean, I'm doing my best to get her situated and stable. I had her stable and then she's wasn't and yeah. And then my husband died. Right. You know, and then life happens. Right. So.

**Eric Jorgensen:** Yeah, it's a question I get all the time from families is who's gonna take over when I'm gone?

**Debra ruh:** Right.

**Eric Jorgensen:** And it, it's not an easy answer, you know?

To that end you, you know, the most, the last package I have is too many moving parts. Cause that's how I feel like all the time, almost all the time is I'm running a business. I'm trying to be the best dad I can be. You know, I, I I'm in a relationship now. I, I wanna be the best partner I can be. But there's just too many moving parts.

How do I, how do I juggle all these? What, what's a glass ball, what's a rubber ball? What can I, what can I ignore? And what do I actually have to, you know, I mean, that's why I try to keep my life is glass ball or rubber ball because the glass balls, you gotta keep them near, the rubber balls, you know, not so, whatever.

**Debra ruh:** I love that. I, I, I'm gonna have to steal that because that is so true. Which balls are you gonna keep in the air? Keep the glass ones. Keep moving the... good. Good, good analogy. Thank you. I will, uh, credit you with that.

**Eric Jorgensen:** Thank you.

**Debra ruh:** All right. Well, let me ask you a few questions that you said I could ask you.

**Eric Jorgensen:** Sure.

**Debra ruh:** Um, only because they're really good questions. What is the biggest challenge professionals like family law attorneys and financial advisors face when working with clients who have children with intellectual disabilities?

**Eric Jorgensen:** I, I think in, in speaking as a financial advisor, when I was a financial advisor, I can't speak to family attorneys. I feel, and I, and I believe that the biggest challenge is they don't necessarily know what they don't know.

Right.

Um, a lot of family law attorneys, a lot of states now are, are authorizing child support beyond the age of 18, which is great in terms of supporting a child.

But it could also have very negative effects on things like social security and Medicaid, supplemental security income, specifically. Because it's a means tested benefit and it's affected by income. Um, it's also, you know, advisors want their clients to move forward on things, but they may not understand why a client is, is so hesitant or doesn't, I don't wanna say care, but the retirement's not their priority because like you just, like you just said.

You, you want, you want your, you, you do hear people say, I want my child. I want to outlive my child, which is horrible.

**Debra ruh:** I know.

**Eric Jorgensen:** So, but it's so hard for a parent, even, you know, myself included to worry about retirement planning when I'm trying to get my son set up and you know, like you pointed out stabilized, I'm in the middle of working on getting him set up with another agency.

**Debra ruh:** Yeah.

**Eric Jorgensen:** I don't care what my retirement portfolio's doing right now.

**Debra ruh:** Nope. Either I gotta protect my daughter.

Yeah.

**Eric Jorgensen:** Yeah. So it's, it's helping these professionals. Um, understand that. And, and those that have children with disabilities, get it kind of, because they're living it. And a lot of professionals, they go into this because they're helpers so that I think they have that intuitive.

They understand something's going on, but if I can give them the, 'Hey, this is what's going on, this is how you can really help your client now', if their concern is, um, what's gonna happen with the child, maybe your focus can be helping them get set up with a service provider or helping them understand 'look your child's 13. You have a lot of years before you have to worry about this. You've applied for the state Medicaid waiver. There's really nothing else you can do at this point. Let's focus on this thing. So it, it, you know, so we don't stay in this constant state of reactivity'.

**Debra ruh:** Right. Right. And I know that my daughter, which was a huge blessing because we don't all get, 'em, got a full Medicaid.

**Eric Jorgensen:** That's incredible. Yeah.

**Debra ruh:** It was wonderful because she was very, very ill and my husband was dying, but we are not getting any services. So I just called in to the head of the agency saying, you know, I'm not getting any services what's going on. She is a full waiver. So, and it's. Their fault it's because times are really hard for all of us.

It just is. There's not enough people to work they're, you know, so we all have to be patient and understand we're just trudging through waste deep mud or, or maybe it's all the way up to our chest and, and still. You gotta get all your work done. Take care of your kids, get your business. Yeah, no, I know my producer, Doug.

He has, you know, two little ones and his, his youngest one has an I E P and his son and just watching what they navigated and Massa. It's just, yeah, it's tough. It's just tough. It's and

Massachusetts, one of better state. I know with mass health. Yeah. Yeah.

And he actually, he put in the, um, the chat window.

Well, actually he's still fighting it. Okay. He still, he had to hire an education advocate, which is what we're talking about and they're still fighting it, so, oh, well, and Massachusetts is one of the better states.

Yeah. I mean, I'm originally from mass, so

no. Okay. I mean, it really, it is one of the best states, so, um, So how can professionals that are supporting families?

Like just this one that we're talking about right now with Doug, um, the families who feel so overwhelmed and they're pushing for the action plan. I mean, where do they even begin, Eric?

**Eric Jorgensen:** So I'm gonna use Doug as an example without really dig. And I don't know him. I don't know his personal story. I'm just gonna use him because it's easier than trying to be of, you know, trying to be.

So imagine if Doug is working with a financial advisor, he's he. He's working with and he is got, he is working with an education advocate to get an IP and the financial advisors saying, well, you need life insurance because if something happens to you, your wife, your children are, are gonna be in a lurch.

And Doug's a smart guy. He knows he needs life insurance, but he, he can't see beyond I, you know, my children, Papa bear. I need to worry about my kids. You know, the odds of me dying are less likely than the odds of my kids suffering because, and, and because it's happening right now with this IEP, mm-hmm so the, what a, what an advisor can do is say, well, okay, I hear you.

And you've hired the education advocate and, and now we're gonna let the education advocate do their job. But what you can do while the education advocate is, is work, doing their job. What you can do is you can start the process for this term insurance or whatever you're gonna. I'm using insurance because it seems to be the most common thing.

It's what I was missing. Um, you know, to, to, to fund the special needs, trust and protect your child. So let's get you started by getting the medical and getting your underwriting started. And by the time you get that started, you're gonna be able to shift, focus back to education advocate and you can let the insurance company do their thing.

So you're really showing, spelling it out for them. And, and, and sometimes. I know I had widower brain. Um, I think there's, I think there's the same thing for parents of children dealing with this, where you, you get so overwhelmed, you can't really think beyond even, you know, I don't care if you've got two doctorate degrees, you can't think beyond the next, you know, what's next for your child.

**Debra ruh:** Right.

**Eric Jorgensen:** So sometimes that professional just has to really break it down. Say you've taken care, you've taken all the steps you can take as long as it's true. And if it's not true, if there's something else that the, the parent can do for the child, Unless the parent is, is like, no kidding gonna step in front of a bus, let, help them get that done.

And you know, let's say Doug didn't have an education advocate yet, but, and he was stressing about the I P then what the professional could do is say, Hey, you know, this sounds like something you're just beating your head against the wall. And maybe this, you know, maybe this is time to bring in a professional.

I know an educational attorney, or I know an education advocate. Let me find, let me facilitate an introduction. I can be in the meeting with you. You know, I know I like this is Eric speaking for Eric. I like to have a third person in a lot of my meetings. Um, you know, when I was, when I was got my cancer diagnosis, I had somebody in there with me because I was overwhelmed.

**Debra ruh:** Right.

**Eric Jorgensen:** You know, so, you know, let me, you know, this is where the financial advisor could say, let me go out and help you get the education advocate. Or the education attorney and, and help you take over, um, if they don't and if that financial advisor doesn't know someone, then they can reach out to me. But you know, a lot of these advisors, they have such an amazing breadth of a network.

They just need to know that. That the family needs to reach out and it, it really comes down to taking that extra step. Um, and sometimes as professionals, I think we get in our own way by saying, you need to do this. I know what's best for you because I can see what you're missing. I think sometimes, and, and maybe I'm just projecting and maybe it is just me, but I think as professionals, we sometimes need to remind ourselves and put our parent head on and say, oh crap.

Remember when I was like that, I needed somebody to hear me. And acknowledge me and, and make sure I was... and address the problem at hand, even if that's not your particular skillset. I'm betting. You have somebody in your network who knows somebody, or you knows somebody that you can re and then really be that value player to the, to the family that you're working with.

I hope that wasn't too much of a rant, but

**Debra ruh:** no, no, no. I thought that was really a good point. I, I thought you made a lot of really good points and I appreciate Doug letting us use him. Not that he can say anything, but yeah.

**Eric Jorgensen:** Thank

you.

**Debra ruh:** But, you know, it, it is interesting when you talk about the action plan, the, you know, tell us more about that because you've talked about the roadmaps you have on your website.

And to be honest, the first thing I wanna do is go out to your website and see what the roadmap is for Virginia, cuz I'm in Virginia. And any of you out there that are in the states, go out, go out to his website once again, truenorthdisabilityplanning.com. I mean, that seems like one of the easiest things we can do, but I know that when I'm, you know, I was concerned, obviously I knew my husband was gonna pass away.

He was actively dying and I went to, I found an attorney and, um, I, I did what we do. I started asking around and somebody recommended him and he turned out that he had two small children himself and coincidentally. He had it a little daughter with down syndrome, you know, that by the way, he was in special needs planning as an attorney before.

Right. And so I liked that he was part of our community. I just liked. And, and I loved the I, Steven Burns, Steven Burns in, um, in Virginia, in Richmond, Virginia, Steven Burns. He's amazing. And the thing I loved about him is that I said, well, should I do this or should I do this? And he would always come up with a plan that I needed.

But I would sometimes think I need this big thing. And he would say, you know, all you actually to achieve that goal and not take, for example, Sarah's rights away from her. All you have to do is do this. And I was like, you're kidding. I thought I had to. Nope. That's all you have to do. Oh, so hiring professionals, it, it really, really, really is needed because it's so complicated.

And I imagine it's not any less complicated outside the United States, but it is very complicated. So should it attorneys and financial counselors and, you know, education coaches and everybody that's in the industry go to your website and get your guides? I mean, so that they know how to do this.

**Eric Jorgensen:** I would love

that.

**Debra ruh:** I think they should, because...

**Eric Jorgensen:** I mean, I I've, I've built road. Yeah. And I've also, you know, um, I'm big on giving a lot of stuff away free. So I've also recognized that federal employees have unique challenges. Unique benefits. Military has unique benefits, divorcing families divorcing with the so I've built checklists that you can get for free on the website.

I mean, these are all, and I'm happy to give it to professionals. I mean, I've, I've, I've given talks, divorce groups, what I'd, you know, what I, what I would also like to see professionals do and, and candidly, I don't know how to do this. I would like to see them make their services more accessible. I mean, when you have an attorney whose billable hours are $350 an hour, that is it's out of reach of so many families, especially the bipoc community.

Um, or, you know, because they're, I feel like they're, they're often very underrepresented and we know they're diagnosis is two or three years behind everybody else.

**Debra ruh:** Right.

**Eric Jorgensen:** So I would love to see maybe, maybe you make planning light packages or you. Maybe you do. And I, I'm not an attorney. I don't, I know a lot of work goes into this, but I also believe there's probably a lot of prepackaged stuff that you have software for and you just fill information in and, and if I'm wrong, you know, I apologize to the attorneys out there, but maybe there's a way.

You can, you, you can acknowledge that. Look, not everybody can afford a five to $7,000 special needs trust.

**Debra ruh:** Well, but

I will also say, um, I will remind everybody that disability goes all the way through the economic, you know? And so there are families that are very, very wealthy and there, you know, families are very poor.

It's everything in between. And so. I don't know if we need to take on and if we could take it on successfully attorney's rates, but I do think you have to find, you have to do your homework and you have to find the attorneys that care about it because just using my attorney, once again, Steven Burns is an example.

He. He, I went to him with that 5,000. Do I have to do this try? And he was like, well, no, all you actually have to do. And I felt like he really had my back. And so I really had expected to pay him a whole lot more money, but he said, but you don't need to do that. Debra, all you need to do is this.

**Eric Jorgensen:** That's interesting.

**Debra ruh:** And so to me, you find. Steven Burn's world. You find the Erics of the world so that we can help each other professionals go out there and look at it. You wanna be a better financial counselor and planner go out and learn this part of it. We need the support. So I, I would love to see what you're doing, cuz I know you've agreed to be part of Billion Strong as one of our global advisors.

Thank you. But I'd love to see some of this go out on Billion Strong because Billion Strong is certainly for the world. But we all learn from each other. Even if I look at what is the plan for Virginia might be interesting to see what the plan is for South Carolina or Texas. And it might be interesting for somebody in Uganda to see what are they doing here, because maybe there's things we can adopt in our country, or we can apply in our country.

So. I appreciate what I've done. I really do.

And there

**Eric Jorgensen:** is some exciting stuff happening over in different countries.

**Debra ruh:** I know.

**Eric Jorgensen:** Um, you know, the UK is doing a lot. Um, yes. I am seeing stuff in Africa about different countries in Africa. A lot of that stepping up and yeah.

**Debra ruh:** Oh yes. And,

and Mina the middle Eastern. Oh my gosh.

They're doing so much in Asia. Oh yeah. Everybody is engaged. But one thing I still think we need to do is do a little bit more of what we're talking about here, sharing information. I also. Don't like hearing that you give so much away for free, cuz that's me too. And you slowly are Fastly starved to death, which I'm not starving to death, but I've had people say, oh yeah, you just do that for free.

Because there are people with disabilities and I'm like, okay, now, now you just made me mad. But, uh, yeah. So we don't want you to do all your work for free because you have to support yourself. You have to support your son. I mean, you, you have girlfriends. So, um, so I think it's time also that we pay people for the work that they're doing, especially if it's adding value.

So I wanna ask you one more question. When should parents start taking action?

**Eric Jorgensen:** As soon as they get a diagnosis.

**Debra ruh:** Everything is important. How do they know where to go

first? Yeah,

**Eric Jorgensen:** I, I, I want parents to take action as soon as they get that diagnosis and this is where again, professionals can help. So if you have a neuropsychologist giving you a diagnosis,

It, it might be different now. I mean, my, my son was diagnosed, you know, 21 years ago. Uh, so it might, it's probably very different now, but when they give you that diagnosis, it would be amazing if they said, oh, your child has down syndrome, cerebral palsy. Um, this, this rare genetic disorder. What have you, here's a list of organizations around the country who can support you or depending on the country you live in.

That can support you. And I don't know specifically what types of resources are out there because, you know, as a, as a pediatrician or neuropsych or what have you, they probably see a lot of different diagnoses. Yep. Um, but if they can have just kind of a, you know here's a down syndrome pamphlet, here's a, you know, what have you, right.

Then that would be a great first step. And they can say parents before you do anything else. Why don't you process what's going on? Here's the names of some support groups to help you process all this, right? Um, and then if you have an intellectual development disability, I want you, I want you getting enrolled with your state and making sure you're on the state's radar.

If, if so, if something does happen, your child's taken care of. And I, I have too many families coming to me whose children are: 25 30, 40, and they're not receiving any benefits. They didn't know they could apply. And it, it, it, it tears me up. It's like...

**Debra ruh:** I know.

**Eric Jorgensen:** Where was the school?

**Debra ruh:** I know.

**Eric Jorgensen:** And it's not fair to the school and teachers to your point earlier, but so who is it?

And this is my, my rant. Who is this gonna beside? Who, who is telling parents? This is what you have to do. This is when, and that's why I built the road map. But I'm not, you know, I, I'm not global, I'm not universal. Um, my guide for parents, if, if you have a child with disability, you're trying to figure out what to do.

I would really like you to think about what is gonna have the most impact over the next three years. Um, you know, so if your child's three and you're ma you're making and you're in the United States, you're making a hundred thousand dollars a year. Don't worry about SSI or medicAid.

**Debra ruh:** Right.

**Eric Jorgensen:** Um, what you should be worrying about is birth to three or whatever that early intervention is called near state or country and getting enrolled, um, getting, getting signed up for Medicaid waivers, even if you don't think you're.

So this is another pet peeve of mine.

**Debra ruh:** That's, I'm guilty of what you're about to

say.

**Eric Jorgensen:** Well, so I've had fam I've had PA families tell me my case manager told me not to apply. Because I wasn't, the waiting list is too long and I won't get services. I don't care how long the waiting list is. If you're not on it, you're never gonna get services.

**Debra ruh:** I know.

**Eric Jorgensen:** If you're on it and they give you funding because this year co a lot of states have more funding because of COVID and we're seeing states we're trying to clean their, their waiting list. Right. Well, if you're not on the waiting list, you're, you're screwed. And I, I wanna shake the case managers that are telling them that I'm sure they're well, meaning.

And they're just trying to save the family frustration. But if you, if you get a diagnosis, put your child on that waiting list.

**Debra ruh:** Well, and let me tell you another thing that we shouldn't do, um, is I just felt so many other people were so much more in need than my family. And so I didn't go on the waiting list and I actually had a good friend of mine scold me and say, Debra, you have to go on the waiting list.

We don't know what the real numbers are. If you don't. And then of course, my daughter got in trouble. My husband got in trouble. Oops. So I also wanted to say that when I was going through that process of get getting the Medicaid waiver, um, I actually had to write that I was gonna let my daughter go live on the streets.

If they didn't help me. I had to say things that weren't true, but I was told by my advisor that if you don't do that, you're not gonna get it. So I had to actually say that I'm gonna throw my daughter out of the house. I'm not gonna take care of her anymore. I was not gonna do that, but that made me mad that that was the game it just made me angry.

**Eric Jorgensen:** To put, to tell the state of Virginia that your daughter is now in crisis.

**Debra ruh:** Yeah, absolutely. Cuz my daughter's in so much trouble. I'm just gonna throw her on the street. Yeah. Anyway, sorry. Little pep peeve there, but.

**Eric Jorgensen:** No I've I share the frustration and anger and the other thing is even if you sign up and I, this is where I, I get so angry. Even if you sign up, there's no guarantee that your child is gonna receive benefits in the state of Connetuicut.

You could sign up when your child is born and the child may never see benefits, cuz there's such a long waiting list and so little money.

**Debra ruh:** Yeah. That's not good.

**Eric Jorgensen:** It's ridiculous.

**Debra ruh:** I know. Well, you know what? I know that I've kept you for 30 minutes and this is what I wanna do. I wanna really encourage everyone to check out his website and check out his podcast because he's doing really, really powerful work.

I'm hoping that we're gonna be able to give him a little grant, maybe Billion Strong so he could build some stuff for us. So. Everybody can get it. So, um, I just wanna be conscious because I know people are gonna say, but Debra, how do we get hold of him? So, Eric, tell people how they can get hold of you and they can see what's on your website.

And I know you're on LinkedIn and things like that. So.

**Eric Jorgensen:** So my, my Facebook and my LinkedIn web, my company websites are true northdisabilityplanning. I'm at, uh, needsnav on Twitter. And, you know, my YouTube channel is, is truenorthdisability planning. And my podcast is ABCs of disability planning.

**Debra ruh:** Cool.

**Eric Jorgensen:** And Eric@especialneedsnavigator.us for the email.

**Debra ruh:** Yes. And also, um, Eric send me all those links and I'll make sure we, we attach 'em to the podcast so that everybody has 'em. But once again, Eric is working in the United States. I know laws are different all over the world, but. He's got some really good resources out there and his podcast is excellent.

So I definitely recommend him. And we're so impressed with him that we really wanna try to figure out how we can take some of his content, get it out on Billion Strong. So you all can see it there too.

**Eric Jorgensen:** Thank you, Debra. And I

wanna, I wanna offer if there's somebody in another country who wants to build something similar, I am happy to share.

**Debra ruh:** Great.

**Eric Jorgensen:** What I did and what worked and what didn't work. And if I could save you some time. Please let me, cause it's been a journey.

**Debra ruh:** Yeah. And you know, wouldn't that be cool if we had some corporate brands that wanted to support that through Billion Strong, cuz I know we have 90 disability persons organization, country partners, 90 countries have joined Billion Strong.

So yeah, we'll talk about that too. So anyway, thank you so much to the audience. Once again, it is true. Disability planning.com and, um, Eric Jorgensen is really making, um, an impact. And I know your wife, your late wife is so proud of you and how you've taken care of her baby. Thank you, Eric. And thank you to the audience and, um, also special thanks to my wonderful producer, Doug, for rust to behind the scenes, bye everyone

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