

John Raffaele: Greetings. My name is John Raffaele and I'm the Director of Educational services at the National Alliance for Direct Support Professionals. And we are here on January 19th, 2022. We are about to embark on a, on a podcast. We are going to be talking with Mr. BJ. Stasio, he'll probably pronounce his name better than I did, in a couple seconds and he'll introduce himself. But the purpose of this podcast is to help the listeners understand the importance of vaccinations, the importance of understanding, the support needs of people with disabilities and the importance of knowing the role that one has as a direct support professional in the lives of people with disabilities during a pandemic. I am joined by my colleague and friend, , Joseph Macbeth. So, Joe who are you?

Joe Macbeth: Hi, good afternoon, John. I am the president and CEO of the National Alliance for Direct Support Professionals and a fellow New Yorker, as is BJ. And I'm really looking forward to having this conversation with, with you and BJ, John.

John Raffaele: Looking forward, Joe, looking forward. Now let's get to, let's get to the talent, Mr. BJ, Stasio. Tell us a little bit about yourself and your situation during, during the pandemic.

BJ Stasio: Sure. I'm , 51 years old, I've had cerebral palsy from birth. I live in Western New York, proud to say, I'm a bills fan, by the way. So glad the bills won have to get that out of the way. Got, got a few more games to go, but that's fine. Any, anyway, the pandemic has been very difficult for me because believe it or not people, I am very outgoing and very social. So the isolation has been very difficult for me to deal with and using all the different forms of technology to communicate like I am today can sometimes be a struggle because you have to use WebEx for one meeting, zoom for another team for another. And it's very hard to keep it straight, but the isolation has been very difficult and my direct support staff were awesome during the, during the time of COVID, they, they stepped up and took care of me up until I got COVID. Then they couldn't come in and help me out. Like they usually do. So that was another layer added, but my staff are very important to the advocacy work that I do. They provide me with transportation. They drive my vehicle because I don't drive because of my epilepsy. So that's important. And without them, I wouldn't be able to do the advocacy work that I do. I appreciate all of them,

John Raffaele: You know, BJ. I just, I heard something, I heard a couple things in there. Let's unpack this because, two things that stood out to me, one isolation. Right. And, it's interesting. We all had to go to this new form of community with each other in these isolating places, meaning these zoom rooms or these FaceTime exchanges. Did you find that was helpful in terms of making you feel less isolated or did it give you further isolation because I've heard both. What did you, what did you get out of all the zoom and teams and, and FaceTime technology?

BJ Stasio: John, well, John and Joe, you know what I missed, and I think you guys know me by now. I missed the experience of getting in people's faces and asking why, because on zoom, they can just mute you and dismiss you and have you leave the room. But if you're in person, they can't really dismiss you. If they walk away from you, you could chase after them. Like I would, I would chase after them until I get the answer I want.

John Raffaele: Yeah. Oh yeah. That, and that's very hard to do in this kind of the platform that, that zoom or FaceTime or whatever these virtual, meeting platforms offer. Absolutely. It, it, it's, it's hard to do advocacy work. Right. And we're going to talk about this in a little bit, your copy written and trademark, I guess, your business, for lack of a better term, the art of advocacy. We'll get to that in a second BJ, but there's something else that you said that kind of piqued my interest. You said the direct support professionals that you have, and that you've worked with, they really stepped up to the plate. What, what were some of the things that they did that were maybe above and beyond their, I suppose their job description. Do you have any stories?

BJ Stasio: Yeah, just taking the of time to find out how I was doing mentally and unpack that because the isolation was extremely difficult for me and not being around the people I work with and for was very difficult. So just to have that extra voice to listen and really care out what you had to say meant a lot and all my direct support professionals do that for me. Like if I'm angry about something they want to hear about it, they're concerned about my feelings, which is more than I could say for some of the people I talk to these days, but my staff are not just my staff. If I consider them my family. And I know that they consider me their family. So that that's good when you work so close together and they, they just understand what makes me tick and what's important to me. And that's what I want on my team. I don't want somebody to focus on those billable units that they all have to do. It's about me as a person and my want for myself and for members of the disability community, who I work with in west New York and around the state of New York.

John Raffaele: It's interesting. When we think about the role of direct support professionals and what certainly our organization, the National Alliance for Direct Support Professionals, what we promote is the, one of the major roles for direct support professionals is to help people with disabilities engage and be part and parcel of the communities. And obviously lockdown happened. Quarantine happened. Did you find that the direct support professionals that you, that worked with you, were they more focused on kind of protecting you and not necessarily keeping you from the community, but did you, did you see their role change to move more of focusing on health and wellness as opposed to all the other stuff that really we want to promote?

BJ Stasio: Oh, you know, it's, it was very tough for them to say to me, "You need to slow down, take it easy. You've done a lot. You need, you need to take a break you to take time for you. You're not looking well." Especially around the time I had COVID they had to kind of put the brakes on and get me to really think about my health, which, which I'm always on the go and on the move. They understand that or help some buddy with their problems before I work on my own. And they have to remind me, I'm the most important thing at this moment. And that's what they all do for me, even though it's annoying, most times I understand it because they have an investment in me as a human being, which is more important than that billable unit, you know?

John Raffaele: Absolutely. Absolutely. Joe, do have a comment?

Joe Macbeth: I do John. BJ you'll recall a few months ago, you and I both testified before a New York state Senate committee on disabilities and you gave really compelling testimony about

how the workforce crisis, the lack of having adequate staff affected your life. Can you share a little bit about that testimony?

BJ Stasio: Well, of course, yeah, I would love to. And part of the testimony was I received two services. I received self-direction via the Office for People with Developmental Disabilities here in New York state and personal care attendance through the Department of Health, which is another Medicaid funded source. I didn't have a PCA for two years. So I slept in my chair for two years. So, I would be ready every day to go to work and, you know, do what I do and just keep going.

Joe Macbeth: I recall that really impacted the panel, the members of that committee. Have you seen any change? Has there been any improvements since that testimony BJ?

BJ Stasio: Well, there's been a lot of outreach to me. Like, how can we help you and my first response is don't help me. There's somebody else who has it worse off than me. Help them. I was just giving the testimony to bring attention that we're all in this together as New Yorkers, whether we have a developmental disability or not, we're all in this together. And one thing that has happened is my connection with the legislative officials that have become stronger. They reach out to me to have the, have the conversations about what can we do to support the workforce going forward. And I talked to Senator Mann's people quite a bit, and Senator Mann himself. So that's been good. But as I said, during my testimony, what, what you saw Joe, when Senator Brooks asked me, what can we do for you? I said, this is not about me. It's about others like me. I'm not here to talk about myself, I'm speaking for everybody.

Joe Macbeth: And you know, that's a really good segue to my next question, BJ and it's about vaccinations. In the public service announcement that we did with you recently, you talked about the need for direct support professionals to understand it's not just about them getting vaccinated, but in supporting people with disabilities. In supporting you is it's important for DSPs to be vaccinated. Share a little bit about that.

BJ Stasio: Sure. If my staff, aren't my direct support professionals, aren't here to help me, I can't do what I do on a daily basis. I can't lead the richer life that the system promises in that mission and value. So if they're not here, I can't do that. So I'd just be sitting at home, sitting on zoom, looking at people who I always look at and saying, gee, I could have done this today. I could have been bothering somebody in my community because I love to go just be a bother to people like I go to this local, this local coffee shop I love. We've had some access issues. So I enjoy going there and making myself super big. So I could fit into those small spaces that they asked me not to go into.

Joe Macbeth: You talk about the greater good. And I think when you talk about people who, who are reluctant and hesitant and refusing vaccines in a direct support role, you talk a about the greater good and I always found that compelling about your message.

BJ Stasio: Yeah, the greater good is we're all in. We all make the system do what it does together without us. There is no system to work for. So if there's no system to, work for, we can't make changes in it together because this DSP fight is not only my fight, but it's a lot of

west, a lot of new Yorkers and a lot of people around the country who are having this same fight. So we all come together to say, it's our system. It belongs to us. It will then change.

John Raffaele: I tell you BJ, that's advocacy, you know, that's advocacy. And I know a lot of direct support professionals that they have a different view of advocacy, right? It's very individualized to the person that they're supporting perhaps and that's fine, but I think direct support professionals, they should begin to look at the bigger picture, the greater good. As you just described in terms of your advocacy work. Tell us a little bit about the art of advocacy. This is your idea, your brain shell. Tell us a little about that. And then I'm going to ask you some questions about how that can help maybe with the vaccination campaign. So go, go for it.

BJ Stasio: Sure. Over this past year, I've met with a local parent here in Western New York, my mentor, and we, we had a conversation about how do we build the future of advocates, because we're not going to be doing this forever. He's in his seventies, I'm in my fifties. And I want to someday sit and just find out who I am instead of the advocate. People always see me to be. So I said, need to build up to few of advocacy. How are we going to do that? So we came up with a system where like there's levels where you start at a white band level, which is, you basically say you're at your life plan meeting or a meeting about you. And you, you say what you want that could entitle you to a white band because you spoke up for the first time, you know, and it's all about speaking up in the art of advocacy is basically telling your story.

BJ Stasio: Like when I first started in advocacy, I had no idea what my story was. Here's the wristband. I don't know if you can see that, but out of advocacy, it's trademarked and there you go. But it's really important to just be able to, to tell you a story in whatever fashion you might, you might want, because it could be something as simple as I want to talk to the lady at the coffee shop today, help me say hello for the first time, because that's how they find out you're a human being, not just a person with a disability, you know?

John Raffaele: Yeah. I mean, that's, I mean, we could have a whole podcast on that right on, on the importance of respecting people with disabilities and understanding them and, and including them, you know, in, in, in our communities. But let's go a little bit more laser focused in terms of advocacy in and around. I'm going to cut right to the chase. How is it for you? What suggestions do you have because you really depend on direct support professionals, but what if you have a direct support professional who is undecided about getting vaccinated? What kind of suggestions do you have? Not only for that direct support professional but for people with disabilities who might be working with people who are direct support professionals who are maybe on the fence about vaccines, what should we do?

BJ Stasio: It's important to have that conversation, but at the same time, respect people's individual choice because that's what we with disabilities have fought for many years, our individual choice. And we have a right to make the choices just as they do, but kind of explain to your direct support professional or those who work with you, how important they are to the way you live your life. Maybe that will say, okay, no harm in

getting a vaccine because maybe they need to hear that from the person they're closest to on a daily basis. If you never have that conversation, guess what? You don't know, if things are going to change until you have the conversation, all that can happen is no, but usually what happens? I get a no, I make sure to have another discussion point down the road later, I don't leave things at a no, you know, because people who work with me and for me are important to my life without them. I wouldn't be the advocate I am today. And I know that

Joe Macbeth: It's funny you say that BJ, because I was just going to ask you what you're describing is a true partnership, a partnership in supporting you and you supporting your DSPs. We always talk about that, a good direct support professional walks in partnership with the people that they support in their life. I think an important piece that we're trying to come across to direct support professionals across the country is that many people with, with disabilities may have underlying medical conditions that make contracting this, virus much more serious than the general population. And we want to make sure that DSPs who care about the people that they support and are still reluctant to get that vaccine that is important for you to know that because as you may be putting people at risk,

BJ Stasio: Yes, yes. And it's, it's also just important to keep that dialogue, just to think, think of them as an extension of who you are as the individual you are, because that's what my staff are to me. Like I, I always talk with my staff about things that annoy me or bother me. We talk, we talk it through, we figure it out and just make it work. And I think they withdraw the line at getting arrested with me, but I haven't pushed that yet.

John Raffaele: That's funny and not so funny. You know, it comes down to one thing and Joe and I talk about this all the time. We've been talking about this for years and years, direct support professionals. They have a very, it's probably one of the only occupations, one of the only professions where it's completely reliant on relationship. Now it's, it's all about having a relationship, being honest, challenging all these things do it respectfully. But ultimately you, you can't support somebody unless you have a relationship with them based on honesty and respect. And that's, that's so clear. I've got one more inquiry. But this we're going to end on a positive note. BJ, is there anything that you experienced during this pandemic? Well, we're still in it kind of, something that has given you hope about humanity, hope about the future, because this has been a difficult time for everybody and anything that has been positive from this experience.

BJ Stasio: Well, it's funny that you, you would ask a guy like me that, but I think one of the things that have come at least clear to me throughout this pandemic has been the art of not only advocacy, but the art of listening. And it's a real skill to take the time to listen. I think more people are listening to each other and support each other. I know in the advocacy community, in New York state, we're doing a lot more of that now than we ever did before. Even though we're all going through the same direct support professional crisis, and we're all trying to support each other through that. But at the same time, I think there's active listening, going on. Like I, how can we help each other, this isn't just about the individual. How can we help each other through this.

John Raffaele: Man? I tell you BJ, that is I think a wonderful way to end this podcast and punctuate it with that's a message of hope. And I think we all need that. I think the world needs more BJs and more BJ Stasio. You are not only inspiring. And I say that not because you're a person with a disability, this is something that unfortunately see a lot of, you know, inspiration porn as it's called. That's not why you inspire me. I'm not going to speak for Joe, but I think he's on the same wavelength as me. It's your commitment, your commitment to changing this system. And, we, we have to have your voice, along with the voices of direct support professionals, along with the voices of anybody that want to see the world a better place for people with disabilities. So thank you so much BJ for your time, today. Keep on advocating, , please stay well. Joe, thank you for your time and we will see you again on our next podcast sometime down the road. So thank you all and, and thank you for listening.