

The Heumann Perspective Podcast
Thriving, Not Just Surviving with Joshua Basile
Transcript

Kylie Miller

Welcome to The Heumann Perspective, a podcast with the internationally recognized, bad-ass, disability rights activist, Judy Heumann.

This episode, Judy interviews Joshua Basile. Josh is a trial attorney, disability rights advocate, community leader, consultant, public speaker, inventor, and so much more. Josh advocates in many different areas, including independent living, transportation, employment and web accessibility. Josh has successfully put forward numerous initiatives and policies at the state and federal level to break down barriers for disabled people. In this episode, Judy and Josh discuss his experience acquiring a spinal cord injury, future goals for Medicaid, the role of mentorship, and much more.

The Heumann Perspective is produced by me, Kylie Miller, and Judy Heumann. So let's roll up, lay down, dance around, whatever makes you feel best. And let's meet this episode's guest.

Judy Heumann

Hello, everybody, and welcome back to The Heumann Perspective. Today we have Joshua Basile who I think you're going to find as intriguing as I have over the last, I don't know, six or eight months as we've been getting to know each other better. I met Josh a couple of years ago prior to COVID, but then we all got sucked down the COVID hole and lots of changes have gone on in his life, and we finally starting to talk together over the last number of months. And I thought he would be a really interesting person to introduce you to.

Joshua Basile

Judy, I'm so excited to be here today, and love you and all that you've done and just to be on your podcast is such an honor.

Judy Heumann

So Josh, when did you acquire your disability?

Joshua Basile

My life was literally flipped upside down when I was 18 years old. I was on an annual family vacation at the beach when a wave picked me up, threw me over my boogie board and slammed me on my head. And that day I shattered my neck and became paralyzed below my shoulders. And I remember floating face down in the water, unable to move, unable to scream for help. But luckily, my friends saw me floating and they ended up flipping me over, and next thing I know I was in a helicopter going to a

hospital. I woke up 14 days later with the ventilator in my neck, unable to speak or breathe on my own. And a few weeks later, I was able to regain my voice and from that moment on, I became an advocate for life.

And I spent many, many years after that finding my voice and strengthening my voice and becoming a disability advocate and learning every single thing I could about this new world that I was being a part of. Because I really knew nothing about disability before my injury. I didn't have any classmates, any family members, any friends. And just it was... It changed everything when I had my spinal cord injury.

Judy Heumann

Now, you were quite athletic before you had your injury. Is that correct?

Joshua Basile

I love sports. Being active, using my hands, my feet. Having competition in my life really pulled the best out of me.

Judy Heumann

So you didn't have exposure to disability. What were your first thoughts when you woke up?

Joshua Basile

When I woke up, really, I wanted just to get back on the golf course or on the tennis courts or just being able to play and play sport and having that be part of my life. But I quickly learned that I needed to heal both physically and mentally and figure a way forward where, you know, life could still go on and continue to move forward. I had so many dreams of being able to finish school, graduate from college, to be able to get a job, to be able to start a family, to have kids. I had just so many dreams in front of me that I didn't know how I would do them, but I knew with the right attitude and the right focus, it would still be possible.

And really, through mentorship, I really found out that I didn't have to reinvent the wheel. Like there was a guy early on in my life, Tim Strachan, who was injured ten years earlier in the same beach as me. And he ended up going to community college, University of Maryland, then went to law school, had a girlfriend and ended up getting married and had kids. And it's just like, if Tim can do it, so can I. So I kind of followed in his wheel tracks and it gave me not only hope, but it gave me confidence that if Tim can do it, I can do it as well.

Judy Heumann

So there was an article in The Washington Post about your injury and things that you had done after. What beach did this occur on?

Joshua Basile

Bethany Beach in Delaware. So it's a popular beach that people in the Washington, D.C. area go to.

Judy Heumann

What did you find out after your injury regarding the problems at Bethany Beach?

Joshua Basile

So the reason why I was able to get connected with The Washington Post after my injury was I was at the University of Maryland, Baltimore Shock Trauma, which is one of the main critical units on the East Coast. And that week of my injury, four other boys came in with spinal cord injuries from the same beach, from the same shoreline. And my mom was like, "What's going on here? Do we need to get a public service announcement out?" Like, vacations are not supposed to end with a life changing injury that impacts everyone in that family for the rest of their lives.

So my mom contacted The Washington Post and they started digging in and researching, and they learned that the Delaware shoreline had more spinal cord injuries than the entire California coastline. And a lot of it had to do with a replenishment program where boats were sucking up sand about 100 yards into the ocean and building up the beach with new sand to protect the homes and make it really pretty for beachgoers.

Judy Heumann

What types of changes have come about as a result of the work that you and your mother and others were doing and The Washington Post? What changes have been made on the coastline?

Joshua Basile

Yeah, after we learned that that summer over 170 head, neck and spinal cord injuries occurred, I believe 40 or 70 of which became cervical spinal cord injuries, we ended up doing a lot of advocacy first within the school systems to let kids know that vacations at the beach are so special and they're supposed to be fun, but there's a safer way of going about it. Did a lot of the local media to be able to spread the word about. But the biggest impact that we were able to have was able to get more and more beach signs there of beach warning signs about safety and being able to understand the dangers that waves can present themselves and that shore break and rip currents can present themselves.

Judy Heumann

Now, I know in the middle of all this, you were a college student, right, when you were injured?

Joshua Basile

I was. I finished my freshman year of college and then came back home and was excited for my sophomore year.

Judy Heumann

And what were you majoring in at that point?

Joshua Basile

Business and then a minor in art. I loved creating things with my hands. So I did a lot of sculpture. Did welding. In the fall, I was going to do glassblowing.

Judy Heumann

When did you start thinking about wanting to be a lawyer and why?

Joshua Basile

So Tim Strachan, one of my first and most important mentors, he showed me it was possible, and I quickly realized that my voice and my mind were my best assets. Physically, I was limited in what I could do, but mentally and with my voice, the sky was the limit. So what can I do to be a true advocate for life, to strengthen that voice and to find my voice and to make sure that every word counted.

So I ended up going to community college, did public speaking courses, then went to the University of Maryland, graduated with a communication major. And then I went to law school and graduated magna cum laude from law school without ever flipping a page with my fingers. That's the beauty of technology. So there's many ways to go about pursuing school. But Tim Strachan taught me that he can become a lawyer, so could I. And the more and more I learned about the law, it kind of brought my voice to the next level of understanding. I really love the law as well because you really don't have to be a lawyer in the respect of having a law degree. It opens the door to so many different possibilities and jobs and career paths by having that ability to think like a lawyer. So I really love that. It was a lot of work, but it was worth it in the end.

Judy Heumann

So as you were going through these significant changes in your life, one of them was now being quadriplegic, using a ventilator to assist you in breathing. You were no longer able to do most things independently. And how did you learn about Medicaid?

Joshua Basile

I learned about Medicaid because I learned I needed it to survive. In order to be able to survive in the community outside of a nursing home, Medicaid is really the only option for the majority of all families in this country to be able to get access to long term care supports, which is that nursing care about attendant care, to be able to live in your

community, in your home, outside of a nursing home. And being paralyzed below my shoulders, I can't get out of bed. I can't go to the bathroom on my own. I can't brush my teeth. I can't do a lot of things. But with the help of a caregiver, I become way more independent. So I'm dependent on caregiving, but I'm independent through caregiving, I like to say.

Judy Heumann

You know, I don't use the word caregiver.

Joshua Basile

What language do you like to use?

Judy Heumann

I use personal assistant.

Joshua Basile

Personal assistant.

Judy Heumann

I use personal assistant because I recognize that people are giving me care, quote, unquote, but I think we think more about taking care of people who can't give directions. And I feel, you know, regardless of the type of disability that you have, one should respect the fact that you can tell-- even for people who are not very verbal-- things that people like and don't like. So I have a dear friend who lives in Sweden, his name is Adolph Ratzka, and decades ago he said, "You know, executives in firms have personal assistants and they're assisting them in many, many different ways." So I use the word personal assistant.

Joshua Basile

Ok, I like that.

Judy Heumann

What does Medicaid provide you in the state of Maryland?

Joshua Basile

So Medicaid provides me access to the Medicaid system, which is a ton of governmental supports to allow me to really not only survive, but thrive in the community. And every state in the country has a different Medicaid program where they get to dictate the rules. But one of the main rules that every state has is the income and asset limit tests that basically require you to be poor. So first, in order to get into Medicaid, if you're a person with a disability, you have to be poor. But then once you're

in the Medicaid system, you can get access to nursing care, attendant care, housing supports, vocational supports. There's many, many different layers of different things that you can get access to, to better quality of life and to live more freely in the community and not have to do it alone.

And right now, I'm receiving both nursing care and attendant care. So I have nursing care that helps me get up in the morning, to go to bed at night. And then I have attendant care during the day that allows me to kind of access all my daily living support needs and being able to really attack my day and do as much as I can and be active.

Judy Heumann

So how has becoming a lawyer benefited the work that you're working on in Medicaid?

Joshua Basile

So whenever there's a barrier, there needs to be a strategy to overcome it. I like to call it the advocacy game. So first you have to recognize a problem, then be able to come up with a solution and a strategy to overcome that. And, you know, there's all these different pieces of the puzzle to make sure that you can get from the beginning to the end to make real change. And so much of it is knowing the system, that it's made of rules, and that you don't have to do it alone. So often people think of a barrier and then they think, you know, they have to do it alone and then it's like, "I can't do it alone." Truth is, you can do it, but you also don't have to do it by yourself. So being able to get a team of people together to create power in numbers. So like, when I wheel down the street in D.C., if I'm wheeling by myself, I turn one or two heads. But if I have like five, six, ten of my friends in wheelchairs with disabilities, everybody's turning their head.

And, you know, one of the best team members that you can bring to your advocacy efforts is your local representatives. So if you want to make changes at a state level, it's so important to connect with your state senator and your local delegates and to get them on board to get behind you. And then learning the system to get the bill through the legislature. It first has to go through a committee. So there's the Senate committee, there's a House committee. So making sure you get champions within those committees to get behind your efforts is a really powerful strategy. And then once it goes through the committee, then it goes to a floor vote. And, you know, being able to get the media behind it so that you can push that to all the different legislators to know that this is important and that they have an opportunity to make real change, not only on a value judgment, but for so many people's lives and that they need to be on the right side of history.

Judy Heumann

I appreciate your giving this in-depth description of things that need to be done when looking at moving legislation forward. And I agree with you that the ability to influence elected representatives and their staff is very important. But if we look at the Build Back

Better legislation last year that the Biden administration introduced, there was a \$450 billion proposal to basically address the Medicaid waiting list. And we were not able to get that through, significantly because of no support from the Republicans. Why do you think it is so difficult when they're seeing people like you and me and we're talking about how personal assistance services and other supports can help make so many people more active and productive in the community? Why do you think there still is so much resistance to really learning about what it is that needs to be done?

Joshua Basile

I think a lot of it is kind of the case framing of the bigger issues. So Medicaid is becoming a divisive issue in the sense of Medicaid expansion and anything that touches Medicaid. It's becoming a partisan issue, which it shouldn't be. It's an investment in the community. And if we look at the community as a short term investment, it's one of those things that you're missing the bigger picture. You know, for someone like myself, I can't flip a switch to cure my paralysis and be able to take care of my daily needs for the rest of my life. My paralysis is not going away any time soon. So it's so important to look at the disability population as a long term investment.

And if you don't do that, next thing you know, the majority of people with long term care conditions or disabilities are going to have a lot of medical conditions, secondary conditions come up and be more costly. So it's like investing early on in people's quality of life, ends up saving so much money in the long term. So I guess if you want, you can try to put it more as a money savings issue. I believe it's more of a value judgment of the quality of life and making sure that people that need the most help can have services needed to not only survive but thrive in the community. But maybe putting it more of a money issue, of both short term and long term, and showing that that investment goes a long way.

Judy Heumann

What are some of the fundamental changes that you think need to be made in Medicaid across the country? Right now, states have so much latitude in how they will use their Medicaid dollars. Which is why there are a limited number of states that have really been moving forward with changes that I think many of us would support. And maybe first, if you tell me which states do you think are doing the best work in the area of Medicaid reform?

Joshua Basile

Well, Massachusetts has always been a leader when it comes to Medicaid. They're usually in the front, showing the way and the rest of the country watches them and learns from them and sees what's possible. One example is the Medicaid buy-in programs. Before those even existed, which they exist for workers with disabilities. So what we were seeing in Medicaid was people with disabilities needed Medicaid to survive. But because of the poor requirement of assets and income, they weren't going back to work if they were receiving Medicaid benefits, because Medicaid required you to

be poor. And if you made more assets and income, you'd lose your Medicaid. So people chose to survive rather than thrive. And Massachusetts said, you know what? Let's try something. Let's do something different. And they created what was in the future going to become the first Medicaid buy-in programs, where they would let workers with disabilities pay a premium and be eligible for Medicaid still, with higher income and asset limits.

And then in the nineties, the federal Congress ended up passing two bills, the 1997 Balanced Budget Act and the 1997 Ticket to Work and Work Incentives Improvement Act and both of those legislative authorities gave states the ability to create Medicaid buy-in programs for workers with disabilities across the country. And every state could design how much income, what assets, whether or not the age requirement of what people could be to participate, and about spousal inclusion. They went very conservative in the beginning days. They thought everybody and their brother would be joining the program which they did not. And now in recent years, in the last five years, we're seeing more and more states basically taking away the limits so that the income requirements can be greater, the asset limits can be higher, spousal inclusion to be removed. Many states have a 65 age requirement where they would force you to retire, and now a lot of states are now lifting that so that you could choose to retire when you want to retire. So I love Medicaid buy-in programs.

Judy Heumann

Which states do you believe have the best programs outside of Massachusetts?

Joshua Basile

So right now, Washington state passed legislation in the last few years lifting the different requirements on income, assets and age, which is fantastic. New Jersey just did this January, lifted all income, asset, age limits and spousal inclusion, which I love what they're doing there. So there's a handful of states that have been lifting those income limits and asset limits and every other limit so workers can work without limits. Which, you know, it's hard enough working with a disability that you don't need limits on dictating your future.

Judy Heumann

Clearly, your work in Medicaid has been very important and you're working on it in the Virginia, Maryland, D.C. area. What are some of your expectations that you are trying to drive forward in these three states?

Joshua Basile

Well, really changing the Medicaid buy-in programs to remove those limits. So both Maryland and Virginia have a Medicaid buy-in program. The District of Columbia does not have a program.

Judy Heumann

I know that.

Joshua Basile

We're one of five jurisdictions and states in the country that does not have it. That needs to change. D.C. needs to be welcoming to people with disabilities. Especially every legislation, every different cycle whether Republican, Democrat, bringing in different thought leaders into the area. We need to make sure we're inviting people with disabilities to have a seat at the table. We also have the federal government, which is the largest employer of people with disabilities. We want to be able to make sure that the federal government can bring those skills and talents and voices to the federal government, especially with disability having a seat at the table.

And this makes me want to actually add one thing that I think really needs to change across the country. Right now, when you're thinking about cabinet level positions within different governors' administrations in different states, there's not enough representation of people with disabilities. It's usually grouped in within health. But the truth is, disability touches everything. It touches health, education, employment. It touches transportation. And one of the things that I really like about the state of Maryland, it's the only state in the country that has a secretary level cabinet position. We have a secretary of disabilities. I would love other governor administrations across the country to have a secretary of disabilities so that they have a seat at the table to talk about all the other different departments and cabinet level areas to make sure that disability is just not kind of pushed in at the very end, but really in the front and forefront of conversations.

Judy Heumann

My audience knows that I am a partisan and I'm a Democrat. And I have to say that, you know, the Clinton administration, the Obama administration and the Biden administration, to some degree Bush administration too-- but nowhere like the other three that I've mentioned and really nothing in the Trump administration--- has had disabled individuals in positions. Not at the secretary level or a deputy secretary, but assistant secretaries and other senior positions across government. So your point, I think, is so very important that we need people in housing, and transportation, and education, on and on, to be able not only to make sure that laws specific to disabled people are implemented, but also, as you're stating, we want to make sure that disability becomes integrated across the work that's going on in these different agencies.

You said a few minutes ago that, you know, you are a strong advocate and you basically after your injury, recognized that advocacy was something that you were going to do and need to do in order for you to be able to thrive. And you recognize early on that changing things A, is difficult, and B, the need to be able to work with other people, which I think is great. And you've also been involved with this program called Fuel

Service. Could you give us a little bit of information about why you decided to start this group and what your expectations are?

Joshua Basile

Absolutely. So often with drivers with disabilities, when we're going to the pump and trying to fill up our gas tanks, it becomes a real struggle. You get to the gas station and you have to honk your horn to help somebody inside, an attendant comes out to help fill up. Or you have to call a million times hoping that they will pick up. Or you have to ask a random bystander to help fill up your gas tank. It becomes a really embarrassing experience, but also one where I've had so many friends that have run out of gas because they'd gone to one station, couldn't get help. Go to another station, couldn't get help. And next thing you know, they're on the side of the road out of gas.

And so I wanted to kind of work with technology to change that. And I learned overseas in Europe that there was an app that was allowing drivers with disabilities to connect with local gas stations to make a kind of a robo call into the station, let them know that a driver was 10, 15 minutes away and that they could come out to help. And basically, with my voice and my different relationships in the States, I was able to bring that app to the United States. And since last year, we went from zero stations to over 1,000 stations using it up and down the East Coast. I'm very optimistic-- I'm a forever optimist-- that we can then now expand it to more and more stations across the country. It's a free service for drivers with disabilities, and it's called Fuel Service, and it's on the app store for Apple and Google Androids.

Judy Heumann

Wow. That's amazing. How do you get new stations to join?

Joshua Basile

So going to each of the brands and letting them know the value this provides. They don't want to be bombarded with honking horns and random people at random moments, you know, improving the communication. So using the app, you're able before you're leaving your home or when you're on the side of the road, you know, 10, 20, 30 minutes away from that station, you can immediately contact them and give them a heads up. So it improves the communication and it streamlines the process. Gas stations want to fill up more and more gas tanks. They want to provide really good customer experiences. It just makes a lot of sense to help the brands across the country provide better services to their valued customers.

So that's the whole idea. I think we've had now six different brands sign up over the last year, and now we're going to be rolling out more and more and more stations. It's really exciting times, but it's so important that we get people to use it. So a lot of times people had their system down. Where they have a family member or friend take their car on weekends and fill it up for them so they don't have to get it done. Now, you can do it

yourself. You don't have to get out of your vehicle. You use the app, you go to the station, you fill up, and you never have to get out of your car. It's a great service and I'm loving that technology now exists to make it happen.

Judy Heumann

So you've also set up a company called Basile Consulting Group. Why did you set it up and what is it doing?

Joshua Basile

So with Basil Consulting, it's basically providing my unique skills and talents over the years that I've developed to help different businesses, corporations, individuals, kind of work with their problem areas that they need help with, especially within the disability community. Being able to do better outreach, marketing, be able to solve different problems, or come up with new solutions to be able to provide better services and to break down barriers. So I'm having companies and corporations around the world coming to me to be able to help kind of be a fixer. And it's really cool to know that my unique voice and the education and the efforts that I put into over the last 18 years have value.

You know, so often people with disabilities are thought of as charity cases and they end up doing work for a company, or a nonprofit, you name it, for free. I did that for 15 plus years of my life. And in recent years I've started to learn that I do have tremendous value and that I can contribute and also be able to help provide for not only my quality of life, but also my family's quality of life.

Judy Heumann

So let's gravitate towards discussing your family. So what's been going on in your life RE: your family?

Joshua Basile

So it's always been a dream of mine to fall love, find a great partner, to start thinking about making babies and to find a way to do that. And I ended up falling in love with Katie, and we met on Match.com and next thing I know, we moved in together. We ended up exploring fertility services, and we learned that we could do IVF together. We went through the process, and then last spring, we ended up getting eggs. We ended up fertilizing eggs. We implanted an egg. And next thing you knew, Katie was pregnant. And a few months ago, Katie gave birth to a beautiful baby boy.

And it's been one of the coolest experiences, most humbling experiences, to be able to enter fatherhood from the beginning days. I'm just continuously find ways with my limited movement to have those moments, those touches with a newborn. And to do everything I can to be the best partner possible for Katie and to support in many

different ways. I really didn't know how it was going to happen because I never went through this experience before. I ended up speaking with a lot of other quadriplegic fathers to learn their lessons, basically to find out different ways of how to parent with a disability.

Judy Heumann

What's the baby's name?

Joshua Basile

His name is Calder.

Judy Heumann

Calder. I really appreciate the fact that you discuss mentoring as being such an integral part of your life. Both people who have mentored you and you mentoring others. I like that you've been giving some very real examples that I think are really very important.

This morning I was talking to my friend Colleen Starkoff. She and her late husband, Max Starkloff, had adopted three children. And when they went to first start and an adoption procedure, they were basically told that Max, as a quadriplegic, would not make a good father. And a number of years later, after they had adopted their first child, Meghan. Max, in his neighborhood, he was going past a gas station and saw the woman who had said he couldn't make a good parent. And he had his daughter, Meghan, standing on his foot pedals with her hands on his thighs. And he just went over to her and said, "I'm Max Starkloff. This is my daughter." And he went and moved away.

It can be so difficult for people to adopt who need to adopt. And also, I think people who don't believe that someone who's a quadriplegic, for example, could be a good father. Have you experienced anything from people where they're questioning your ability to be a good parent? And what kinds of supports have you been getting?

Joshua Basile

I've not been questioned yet just because we're living in the COVID days. So I don't really leave my house that often. But with that being said, it's just so much about parenting is putting the time in. You know, a mother is not a better parent than a father just because they're a mother. It's about practice. It's about putting the time in, the effort in and making those touches. So I'm trying to make sure that I put forward enough time, put enough effort in, be creative and just finding different ways to contribute to the family. Not only the kiddo, but also my partner and the rest of the family. It just takes effort.

Judy Heumann

How has fatherhood changed your perspective?

Joshua Basile

Fatherhood has absolutely given me more respect and love towards my parents. Just the sacrifices they made to bring me up, to keep me alive, to exercise both my mind and my body, and to give me all of the different opportunities that I had as a child. There's just so many layers of sacrifices that I never, ever really even appreciated as a kiddo. And to be able to now go through the process of being a parent and what it takes to do it well.

Judy Heumann

It sounds very exciting. What is an important message that you would like to share with the audience?

Joshua Basile

It's so important to be able to not have to be on a journey alone. You know, it's all about kind of understanding that if barriers exist in front of you, they're meant to be broken down. And it's just a matter of finding a way and not doing it alone. Getting powers in numbers. Coming up with a strategy. So every day at least, I'm always trying to find ways to break down barriers. And right now, the biggest ones for me, circle around independent living, employment, transportation and web accessibility. All of those different areas impact not only my life, but millions of families across the country. If we can do more to bring more awareness that workers with disabilities have incredible skills and talents and that they can provide incredible opportunities, or basic options for businesses to do better and to be more inclusive within their workforce and improve their operations and reach more and more businesses. Like it's amazing that people with disabilities have a spending power of over \$490 billion. And even with like web accessibility, less than 2%, at least last year, were accessible websites. This year in 2022, we're now at 3%. So we're doing a little better. But those numbers kind of a joke. We have to do better.

A lot of people think of an accommodation as a weakness, I don't. I'm always thinking of accommodations as creating an even playing field, or as providing strength to you. To give you the tools needed to be able to do what you need to do with your day. So after my injury, I ended up falling in love with sailing, adaptive sailing. So I actually do a sailboat with just my breath. With one straw I control the rudder, another straw I control the ropes that control the sails. And I think of life now as a voyage and a journey that you have to be on and you need to become the captain of the ship. Of your ship. And because the truth is that in order to do that, you need to learn to become your own best advocate. Because nobody is going to fight harder for you than you're going to fight for yourself. And with that being said, on this voyage and to be the captain, you don't have to do it alone. If you do it alone, it's going to be a much harder voyage. But you can have friends, family members, personal assistants, government support programs. You can have so many different people and programs be a part of your life to get you on your journey. And to not do it alone is a good thing because you don't have to do it alone. It's just up to you to decide what path and what direction you want to go in in life.

Judy Heumann

What is the most exciting place you've taken your boat?

Joshua Basile

So I ended up chartering a catamaran from the coast of Florida to Cuba. And that was a wild adventure going down there. I ended up introducing a sport I invented called Slingshot Golf to another paraplegic in Cuba. And it was a wild adventure to be able to go down there and come back and to tell the story.

Judy Heumann

Did you take the boat from Florida to Cuba and Cuba to Florida?

Joshua Basile

Yeah from Key West to Cuba and back. And we ended up bringing two other families impacted by paralysis. And it was a wild adventure with friends and so many good stories.

Judy Heumann

Well, I have one final question. And that is, what is something that our audience doesn't know about you that you would like to share?

Joshua Basile

So I'm a pretty big adventure seeker. I love getting outside of my comfort zone. I'm a big believer of if you have a willingness to try and a little creativity, you can do just about anything. You might be doing it differently than you did it before or differently than any other person that's going about doing it. So like with with my nonprofit, Determined to Heal, we take families-- or at least before COVID we did. In 2019, we had 150 different families that we brought on 450 different adventures. It could have been something like Slingshot Golf to adaptive skiing, surfing, indoor skydiving, you name it. So I love being able to, not only for myself, get outside of my comfort zone and turn heads, but bring in other families. Really any excuse to get outside of your home and live life and to change perspectives of everyone around you.

Judy Heumann

Sounds great. Have you done skydiving?

Joshua Basile

Not yet. And I love always saying "Not yet" because it's something that's on my bucket list. Becoming a father has kind of... I don't know if it's going to change me with my adventure kind of perspective because I've got a few more responsibilities these days. But yeah, I would love, love to go skydiving. There's a cool adventure out in Utah that I

want to do. It's like a bobsled on wheels and with paragliding and basically you wheel off mountains and you just end up, like, just floating and going through the sky with somebody behind you. I feel like I could get behind that.

Judy Heumann

I'll watch you. Well, I really want to thank you so much for taking time for this discussion. So many great things that you're working on with so many other people. Medicaid for me, too, is a huge issue. And being able to get a program which really is more consistent around the country so that people don't have to be worrying about what state they're living in, which right now clearly is an issue. And for all of the joy that you are bringing into the world with your family and the creative things that you're doing. So I look forward to staying in touch. Thank you.

Joshua Basile

Thank you, Judy, for all that you do.

Kylie Miller

Now it's time for Ask Judy, a segment where Judy answers questions sent in by listeners.

That was a really informative episode. I learned a lot through Josh.

Judy Heumann

Yeah. Josh is a very interesting man. He's done so many things since he became disabled. He certainly has really both looked at areas of need that he has had and also worked with other disabled people trying to address issues like Medicaid buy-in.

Kylie Miller

Yeah, and he's been doing a lot of work in the state of Maryland. So I thought this question for Ask Judy might be fitting. So we have a question from "Justice is like Air" on Instagram. The question is how can I best address systemic disability discrimination in my state?

Judy Heumann

It's a great question. And I would say that you should first look to see whether or not there is a statewide coalition on disability. Or if there are any national organizations that may be specific to your disability. Or whether you're involved with independent living centers in your state. Or the state Independent Living Council. Or other organizations like NAACP or whatever particular groups may be at your state level. But that would be one thing, which groups are there and what are they focused on?

And maybe even before that, I would look at what are the areas of concern that you have. So when we look at Josh, home and community based services is a very important issue for him, both personally and then for so many other disabled people. And so the way the programs work, you know, there's federal money and then states have the prerogative to set programs up in a particular way that's not uniform from state to state. So that's another area, particular area like Medicaid. But there may be many other areas that you're interested in that directly or indirectly deal with disability. Like statewide groups on environment.

So I think, you know, what's important is that there's a lot of work that does go on at the state and local level. Frequently, it's also linked to the federal, but also states are driving, you know, their own trains in many ways. And so it could be a great opportunity for you to select the area you're interested, look for organizations that are working in that area and see if you're interested in joining them.

Kylie Miller

Great. Thank you, Judy. And thank you for the question. And if you're listening and you have a question for Judy that you want to hear on another segment of Ask Judy, please send it to media@judithheumann.com or DM Judy on Instagram and Twitter.

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