BoggsCast Episode 17: The Work and Legacy of Judy Heumann

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JAIME ZAHID: Welcome to the BoggsCast, where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts.

Part of Rutgers Robert Wood Johnson Medical School, The Boggs Center is New Jersey's University Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities program. I'm Jaime Zahid, Training and Consultation Specialist. In this episode, we'll be discussing the work and legacy of Judy Heumann, disability rights activist, who has been coined as "the mother of the disability rights movement" by many.

We sadly lost Judy a few months ago and wanted to take some time to honor her memory through this conversation.

I'm joined by my colleagues Steffen Klenk, Marlene Brockington, and Steve Gruzlovic, all of whom have lived experience as people with disabilities.

Steffen is a recent graduate of the New Jersey Leadership Education in Neurodevelopmental Disabilities program, otherwise known as NJ LEND, and a Partners in Policymaking graduate for the class of 2020-2021. He is a self-advocate, photographer, and journalist who is passionate about employment and aiding to improve the lives of others.

Marlene is an advocate who graduated from the Partners in Policymaking program in 2020, and has went on to be a part of many different panels and groups that are all focused on inclusion and improving the lives of people with disabilities.

And last but certainly not least, Steve is an advocate and consultant for businesses and individuals with disabilities and their families. He currently serves as Advocacy Discipline Coordinator in the New Jersey Leadership Education in Neurodevelopmental Disabilities program at The Boggs Center and as Board President for The Progressive Center for Independent Living. Steve hopes to continue to help as many individuals as possible, while legislating and advocating for a naturally inclusive society for all.

Steffen, would you like to start off our conversation today? I know we wanted to start with chatting about how Judy impacted your life and your advocacy journey.

STEFFEN KLENK: Yes, absolutely. And thank you for that wonderful introduction. And I am very proud to be part of this discussion today.

I would like to start with a little bit of my advocacy journey. I was diagnosed very early in my life with pervasive development disorder, not otherwise specified, also known under the abbreviation of PDD-NOS. Shortly after that, I was diagnosed with autism spectrum disorder. Growing up, I didn't have too many friends who were diagnosed on the spectrum. In fact, back in middle school, I was one of, if not the only people, in my school who was diagnosed.

It has been a very interesting journey since then. I started doing a lot of research on my disability, what it meant for me, and how that would impact me going forward. And the number of people that I've met along this journey has been so impactful.

And then when I joined Partners back in 2020, I heard about this impactful woman named Judy Heumann, who was brought up during conversation. And that, to me, began a deep dive into learning more about her life, and her advocacy, and how she not only helped make me a better advocate, but a better person. She really did leave a mark on many individuals through her activism and her work. And that has really driven me to become the best advocate that I could possibly be and to make this world just a little bit better.

JAIME ZAHID: Thanks for sharing, Steffen. I just learned some stuff about you that I had no idea. Marlene, Steve, did you want to add to that conversation?

MARLENE BROCKINGTON: Yes. Hi. Thanks for having me. Like Steffen, I was introduced to Judy Heumann through Partners, and from there, I've read *Being Huemann*, her book, and we have a lot of similarities.

Like her foundation, with her family, they really pushed her to be the person that she was. Her mother was instrumental of pushing her to go to school and making that a priority, which pushed Judy to want to do things for herself, much like my parents. I was always pushed to do things to the best of my ability.

STEVE GRUZLOVIC: Judy had a tremendous impact on society and culture as a whole, not just for this country, but for around the world. If you were able to see her memorial service when she passed away, she had speakers from all around the world come and presidents from a lot of the countries discuss her impact that she had. And she's considered the mother of the disabled rights movement for a reason, because she dared to go where no one had gone before in that space.

So, I think she had a tremendous impact because a lot of times now, within society, we fight for different opportunities that we want, and she was simply fighting for an opportunity to live and to function as an individual in mainstream society. So, she was a true trailblazer and a trendsetter. And a lot of people used her impact and her story for motivation today.

JAIME ZAHID: Absolutely. And I always, since I've learned about Judy, found it interesting. I feel like she didn't set out to be an advocate. She set out to be Judy Heumann who wanted to live her life, which I guess is probably true for most advocates.

STEVE GRUZLOVIC: She came to speak at Rutgers during the 2020-2021 year, I believe, and she said that she hated the term "self-advocate", because it was really individualistic and she preferred the term "advocate", because at the end, we're all advocating for something. So, I think that's more and that's true. Her whole life, she set out to just have normal human experiences that we would all take for granted. But unfortunately, she had to advocate to be able to experience those.

STEFFEN KLENK: Yes. And adding to Steve's point, we are all our own advocates. We're all fighting for the same thing. And in some ways, we're fighting for what we believe in. I remember growing up and my mom has always been behind the scenes. She was always attending meetings, conferences, getting herself educated.

And back then, I was not ready for that. I didn't know what autism was, but also, back in the time when I was in middle school, so very few people were diagnosed. So, now I'm taking on the reins and really stepping foot into this wide world of advocacy and meeting the most profound people on the face of this planet, and that makes me really happy.

JAIME ZAHID: I love to hear that, Steffen. I know that we all watched Crip Camp. What are some key takeaways that you all had from that film?

I know for myself, I was so impacted by the fact that it seems to have been such a typical camp experience, despite the limitations of physical supports and the, in retrospect, the lack of assistive technology at the time.

So, of course, there was much more that could have been done if the times were different and supports of today were available. But I did leave that film thinking to myself, wow, that was a really typical camp experience.

Marlene, you want to start us off?

MARLENE BROCKINGTON: I'm a crier when I watch TV and movies or anything good, so I cried. And it really made me feel like I missed out when I was younger, because I got the opportunity to go to camps like that and I never did it because I was a homebody. And it really made me wish I had took the leap and gone to camp, because it seemed like so much fun, just being around people that were like-minded and growing and cultivating. It was really cool to see.

STEVE GRUZLOVIC: Yeah, I also cried when I watched the movie as well, because it was very nostalgic for me of when I went to camp.

And I agree with you, Jaime, there's a lot of sort of typical camp experience things that happened, but there's also a deeper meaning to that movie, which was that camp experience was one of the first ground breaking grassroots efforts to really organize a disability rights movement. And even now, today, a lot of the camps that you would attend in today's times, they don't do this so much anymore, but when I went to camp, I got recruited to go to college. That's how I went to college.

And now, the people that I went to camp with, a lot of them I'm still in touch with and we lead a lot of advocacy efforts now. So that movie and that camp structure still resonates today, and it still founded some of the movements that you're seeing today. But that was the original movement where they organized, which I thought a lot of the footage was really great to see.

Some of the cultural things that they talked about, like the one lady, she went to the doctor and they thought she was pregnant and she wasn't. She wasn't pregnant, but she experienced one of the same cultural norms that we would experience today.

JAIME ZAHID: Yes, absolutely.

STEFFEN KLENK: It was really eye opening to see that film for the very first time and hearing the stories that came out of Camp Jened and how it became a springboard, really a launching point, for the disability rights movement, and just the stark differences between life at camp versus life at home. At that time, in the 1970s, I can't imagine a world where people weren't treated equally or had the same rights as everyone else. And what really stuck out to me in the film was seeing the 504 sit-ins in San Francisco and how very few media outlets were covering this story.

As someone that writes for a living, as a journalist, we all have a story to tell. We're the ones that have to tell the stories and spread the word about disability rights and how vital that is for our society.

But to see that film and watch how it led to so many other movements, including the Capitol Crawl in D.C. and the passing of the Americans with Disabilities Act, or the ADA, I think every person in the country should watch this film. You will not have a dry eye after you watch it, I guarantee you.

JAIME ZAHID: I love how we're all sharing the emotion that came from Crip Camp. I actually hesitate to share that sometimes because some people laugh at me. I'm a very emotional person, and yes, it did make me cry too.

Also, Steve, I wanted to touch on you talked about how much footage they had. I forgot to mention that before, that I was quite impressed that given the times, I mean, it wasn't that far back in history, but far enough back that they didn't have smartphones where they could just pull out and grab some quick footage.

And Steffen, you had an excellent point about the lack of media coverage of any of the advocacy work that was done back then. And truly, I feel like that's something that still is occurring today, that there is a

lack of media coverage or even just coverage on social media. I'll scroll social media and there's quite a few algorithms that I've gotten pinpointed into, even the disability rights algorithm. There's not all that much there, which is pretty disappointing.

STEFFEN KLENK: Yeah, this is something that really frustrates me. As a writer in 2023, we're seeing a lot of shift where there are very few outlets for information, especially on a local level, and that's really shocking.

I can tell you that where I live right now in Southern New Jersey, we have had a major shift in the print media industry where newspapers and web outlets are only publishing at certain times during the week instead of having a daily format. And this does have an impact on the disability community, because information needs to get out there and we need to have a place for these stories. No one else is going to tell them. We need to be the ones to spread that information. And when there are so few outlets that are around, you're not going to be able to hear about them.

So, this is very vital. I do hope that people are staying informed because that's how things get done. That's how action is taken.

JAIME ZAHID: Absolutely.

MARLENE BROCKINGTON: Yes, it definitely is important. I'm a journalism major where I go to school and that's why it's important to have outlets like this and for us to create our own outlets so the information that's important to us will get to the people who need it.

JAIME ZAHID: For sure. So when you all think about the name Judy Heumann moving forward, what do you think is the legacy that's going to come to your mind?

Steve, do you want to start us off with that conversation?

STEVE GRUZLOVIC: I think that she was a major catalyst to a lot of the movements that we continue to have now. I think, obviously, in modern times, today, we're still fighting for some of the same issues, unfortunately, that she fought for so many years ago. And she continued to work tirelessly, up until the point that she became ill and passed away, to combat some of these issues.

But I think as a part of her legacy and in support of moving forward, we really need to do some things in order to make it better. Some of those would include individuals with lived experience be at decision making points when it comes to making determinations about certain programs or on certain issues. You really need someone with lived experience in there. Because, unfortunately, at this time, there's not that many key leaders and decision makers at those points. And that was one of her main points in a lecture that she gave at Rutgers, was that we need key decision makers with lived experience.

I also think, unfortunately, there will never be such a thing as the term "normal." I hate the term "normal" because, what is normal? That's very hard to define. We're still going to have to fight for the same things and it's going to be an ongoing evolution for disability rights.

And I think it's important for people to understand and I think it's important that Judy taught us, disability can happen at any moment. Any one of us could be disabled and need help at any moment. It's the only group in society where you're almost 99% guaranteed to join whether you want to or not. And the circumstances at which you join, it's not really up to you.

So I think we really do need to follow her model and her legacy and start combating some of these issues like housing, employment, access, financial means and financial gains incentives, and just advocating for everybody overall to live a more naturally inclusive type of society and not just be, oh, the individual with a disability, but have that be a part of your story and not the whole story. I think that's also important too.

JAIME ZAHID: Thank you for that, Steve. And I have to agree with you on that. Your reflections on the term "normal" because, exactly, what is normal?

STEVE GRUZLOVIC: It's a washing machine setting.

JAIME ZAHID: Yeah. I love that. I'm going to remember that from now on and think of you.

Steffen?

STEFFEN KLENK: You made such great points, Steve, and my goodness, that is such a great way of putting it. What is normal? I mean, none of us would be sitting here today if it weren't for Judy Heumann.

The mark that she has left on society has really made such an impact. And I know I've used that word quite a bit, but her persistence and drive to make the disability community, really the community in general, a better place is life changing. And now is the time where we really need to start having conversations. People need to join in the fight for disability rights across the board no matter what it is. Whether that is joining a group, whether it is talking to individuals, politicians, whoever it might be, we need to have a voice. We need to be able to speak up. We need more people like Judy Heumann in our society.

I'm really grateful that I get to participate in the Regional Family Support Planning Councils in our state because it allows me an opportunity to hear about the issues that are impacting my local region, and not just the region in general, but the entire state and also on a federal level.

So, be part of the conversation. Have your voices heard. We need those voices amplified in more ways than we could ever imagine.

STEVE GRUZLOVIC: To follow up on Steffen's point, I think another great part of Judy Heumann's legacy was that she was a connector of all people.

STEFFEN KLENK: Yes.

STEVE GRUZLOVIC: And I think part of the problem that we have, in this state especially, is a lot of the services and a lot of the organizations that deal with disability and disability related services are so siloed and they really don't get together to promote positive action amongst everyone. And I think part of her movement, and part of the movement movie, and part of her book, and her international exposure, she was really a connector that connected all those people and organizations together to really promote positive change. And I think if we want to do that, we have to replicate that on a much, much larger scale, to serve and promote the most impact possible.

MARLENE BROCKINGTON: I would say to keep her legacy going is to know all you can know. Knowledge is power. It's important that people with disabilities, people in general, know their rights. There is a lack of people knowing their rights.

In order to fight for something, you have to know about it. So that's important. Judy was known for being feisty and fighting for what she wanted and helping other people do the same. So, stay feisty.

JAIME ZAHID: I think those are some excellent notes for us to end on.

Steve, your call to action, for groups to get together and stop being so siloed.

Marlene, a perfect note to end on, to stay feisty. I am very sure that Judy would definitely condone that idea.

I do want to point out to our listeners, I think Steve has mentioned more than once, and thank you, Steve, for the plug, that you all can listen to the lecture that Judy Heumann did for The Boggs Center. It was back in October of 2021, and it was excellent. Visit our website at rwjms.rutgers.edu. Go to the home page, and then to Resources, and then Video Library. You can search for the Fall of 2021 recordings and listen to the lecture that Judy Heumann did.

So unfortunately, that is all of the time that we have for today. All of these podcasts, any time I record, I always think to myself, my gosh, I could really sit here and talk on this topic for so much longer.

Does anybody have any final closing thoughts?

STEFFEN KLENK: I would like to say that what Judy Heumann meant to me, as an advocate, has changed my life. There's no other way of putting it. If you have the opportunity, watch her TED Talk that she did back in 2016. It is on YouTube.

It's 17 minutes long, but I guarantee you, it is worth the watch. And like I said, watch Crip Camp. It will bring a tear to your eye, but you will also be informed.

And never forget to stay informed and always keep learning.

MARLENE BROCKINGTON: As we all have said, her impact was tremendous and will keep going for future generations. She's a part of our lives every single day. Every time we are able to be out in the community, that's a little bit easier because of Judy Heumann. So, her impact is truly unprecedented, and she will be missed, but she will never be forgotten.

STEVE GRUZLOVIC: My closing thought is, her and her work are definitely going to be timeless and it's definitely going to be a heavy influence for future advocates moving forward and we need more people like her.

Like Marlene said, she was feisty. She was a firecracker and she was unafraid. And I think that if more people with disabilities could adopt that attitude and lifestyle, the world would be a much greater place.

JAIME ZAHID: I would like to thank our panelists, Marlene, Steffen, and Steve. Thank you all so much for your insightful remarks and wisdom on this topic of Judy and her legacy. We do appreciate it.

Thanks for listening to this episode of BoggsCast, a podcast by The Boggs Center on Developmental Disabilities. A full transcript on this episode can be found at theboggscenter.podbean.com.

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