

## You First Episode 42: Remembering Judy Heumann

**Keith Casebonne:** You're listening to You First -- The Disability Rights Florida Podcast. On this episode, we celebrate the life and accomplishments of Judy Heumann.

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**Keith:** Thanks for listening. I'm Keith.

**Maddie Crowley:** I'm Maddie. On today's show, we're going to take some time to talk about the life and legacy of Judy Heumann. For folks who may or may not know, on March 4th, 2023, the world was pretty much shocked by the passing of the legendary disability rights activist and leader, Judith, or more commonly referred to Judy Heumann.

She's considered the mother of the disability rights movement, and frankly is a badass. She was essential to the disability rights movement, disability rights advocacy, and progress. It's really because of her advocacy that organizations like ours can even do the work that we can do today.

We really are indebted to her, and her work, and her advocacy. We'll definitely continue her fight for disability rights after she's moved on, in her honor. To honor her, we wanted to do a special tribute talking about who she was, and her advocacy, her accomplishments, and frankly, just her long-lasting impact, her presence that she'll forever have on the disability community and the world.

**Keith:** Yeah. Let's kick in just about who she was and her background. Her family's actually originally from Germany and the family is Jewish. This is happening during the '30s and '40s, during the Nazi regime.

In 1935, Judy's family came to the US, eventually settled in Philadelphia, and Judy was born in 1947. A number of her family were murdered in the Holocaust, and so that adds perspective to who she was.

She really grew up in Brooklyn. At 18 months of age, she contracted polio, which was another huge thing happening in the '40s. Because of that, she used a wheelchair for the majority of her life. Even as a young child, she was in the fight. She had to struggle and fight for her rights.

First of all, her family had to fight just to get her included in school, just to get her into school because, believe it or not, local school officials there, they considered her a fire hazard.

**Maddie:** What an inhumane thing to say about somebody.

**Keith:** I know. A human being is not a fire hazard. Ultimately she received home instruction a couple of times a week for an hour, which seemed not quite enough, but that's what they were given.

**Maddie:** Bare minimum.

**Keith:** Yeah. Bare minimum. Her mom was an advocate and helped fight to get Judy into school. She comes from a family of advocates. Still, it was a struggle. It was a challenge to maintain

access to schools. Back then, '40s and '50s, there was no legal mandate demanding any inclusion or accessibility in the education space. Always a struggle.

**Maddie:** Some historical context and things in her book, noted that even though she finally got access in middle school and things like that, she still struggled throughout high school and college, which we're going to eventually touch on. Around this time of her life is when she started attending this camp, this camp for other people with disabilities called Camp Jened.

For those listening, you might be familiar with this. This is the camp that's featured in the now very famous Oscar-nominated film "Crip Camp," that documents the origins of the disability rights movement, starting with that community attending Camp Jened.

One quote comes up when folks talk about Camp Jened is, "We had the same joy together, the same anger over the way we were treated, and the same frustrations, and opportunities we didn't have."

It really was this really important space when thinking about the origins of disability organizing, the disability rights movement. It was really in these community spaces, that people with disabilities who have experienced barriers like Judy in education, or healthcare, or even the ability to navigate the area where they live, it was this space where everybody was given their access needs.

They were given to participate in the camp, in that community. It really was this place that barriers and ableism fell away, and that people could have the access that they just needed when it was normalized, compared to what they experienced in that non-camp space.

**Keith:** It's sad that at that time, a camp was needed to feel that way.

**Maddie:** Yeah. It's really interesting because as someone with a disability, I have a form of muscular dystrophy and grew up going to a camp for kids with muscular dystrophy, and other related conditions. I went starting in early middle school when I was just a preteen.

At that time, that was the first time I had ever experienced what full inclusion and access was supposed to be like, and what it felt like, and the ability to be around people who had similar bodies, and ways of moving, and different needs.

It really was such an impactful space for me to be a part of. It just goes to show how impactful these spaces are for people with disabilities and their ability to build community and establish a sense of self and community just like Camp Jened. This is a really cool aspect of disability history, so I definitely recommend checking out Crip Camp and some of the history around this.

**Keith:** It's a fabulous film. If you have not seen it, you definitely need to check that out for sure. She graduated from Long Island University in 1969 and had planned to be a teacher. In 1970, she passed any exams that she needed to be a teacher, but apparently just news to me, at least then you had to have a physical exam to be a teacher.

**Maddie:** Yeah. I was reading into it. I guess, the reasoning of this, what ended up being this court case, was that she wouldn't be able to get children whatever age that she was teaching, out

of a building during a fire because she herself would maybe experience barriers getting out of a building, which is a whole other conversation.

I was mind blown because you don't need to be non-disabled to teach. It's like a...Anyways.

**Keith:** You're right.

**Maddie:** All very wrong reasoning.

**Keith:** It's really fascinating. She was denied that and you mentioned the case. Yes, she sued the city of New York, the Board of Education for the city of New York, specifically, and that case got some press. In fact, there was a headline in one newspaper, referring to Franklin Delano Roosevelt having been President, "You can be president, not teacher with polio."

It was an interesting perspective. Like I say, it got some press, and the case was ultimately settled, and Judy Heumann became the first wheelchair-using teacher in New York City. We're seeing this life of advocacy, and struggle, and fighting for what you need.

**Maddie:** Definitely. It's because of this court case that a lot of people with disabilities around the country started following her. They were sending her mail, sending her just letters of appreciation and acknowledgment of her fight to bring more access and equity for people with disabilities.

Because of this, she realized the need for more of this work, and obviously being a lifelong advocate already at this point in her life was, like you said, start down this path. She and several of her friends created an organization called Disabled in Action, which was all about really getting out and doing political protests to start demanding more civil rights for people with disabilities.

It's really important to know at this point, in 1970s, early '70s, people with disabilities really didn't have many rights at all. People were, and still, but were living in institutions in really bad situations. At this point there really...

**Keith:** There really were no laws.

**Maddie:** Exactly.

**Keith:** There was none to mandate anything.

**Maddie:** Exactly. This is where Judy saw the future of her life and advocacy could take off. One of the more famous protests from this organization called Disabled in Action, one of the many things that she ends up being a part of in her life included the famous traffic-stopping protest in New York City on Madison Avenue.

Over 80 activists with disabilities blocked that area of the road, in protest of President Nixon vetoing early versions of the Rehabilitation Act, which would have been a pretty important law starting the move for disability rights and disability rights access. We'll definitely link to some of that coverage and some photos from that. That was a really important thing.

That was one of the first of its kind of this major politicized disabled advocacy or activist event, and really getting out in the public and showing like, "We are here, we're disabled, and we're going to do everything we can to really demand our civil rights, which is exactly what they continue to do.

**Keith:** Groundbreaking at the time.

**Maddie:** She then moved to California to work for the Center of Independent Living, where she continued a lot of her disability-centered work. She was also really crucial in the development of the legislation that ultimately became the Individuals with Disabilities Education Act, commonly referred to as IDEA.

This is the law that still protects students with disabilities today. One really cool part of disability history that I definitely wanted to highlight on as we were getting this background, was the 504 sit-ins.

**Keith:** It's a good story.

**Maddie:** I always love telling people about this because it's so cool and such like...anyways, we'll get into it. In 1977, a man named Joseph Califano...and for disabled folks listening, they might be cringing at that name because he's not a beloved person in the disability history.

He was the Secretary of Health Education and Welfare at the time. He refused to sign regulations for Section 504 of the Rehabilitation Act of 1973, which was the first US federal civil rights protection for folks with disabilities.

Because he continued to refuse to sign these regulations, disabled protesters occupied the AGW, which people just refer to as HEW Federal Building. Despite everything Califano did to try to force them out by denying them food, their medication, very awful stuff...

**Keith:** The irony of the Secretary of Health Education and Welfare denying people food and medication. Anyway, sorry, go ahead. [laughs]

**Maddie:** He's a very not beloved historical figure for disabled votes. Thank you for pointing out that irony. Disabled people are clever. We are scrappy. We are definitely smarter than him. The protesters worked closely with other organizations to get food and the medications, and different things they needed delivered that next day.

There was a lot of organization and disability community collaboration that was happening behind the scenes very skillfully, and in a way that Califano and other folks just simply were not expecting.

What I also really like about talking about...this is also a really important moment in history for cross-movement organizing, both with the disability community and the African American community.

This is because Brad Lomax...you might have heard of him. He's a really famous historical figure in disability history and is one of the big organizers in disability rights history.

He was also a part of his community's Black Panther Party and was integral in organizing the Black Panthers to bring the protesters participating in the sit-ins, the food and snacks, and everything that they needed to maintain occupation of this building.

The Black Panthers are often acknowledged and credited for a huge impact in the ability for these sit-ins to succeed. What's cool is that these sit-ins actually lasted almost a month. They were 28 days long.

**Keith:** That's incredible.

**Maddie:** Just the longest sit-in in American history, which is wild because we have such a rich protest and civil rights movement history, where sit-ins were often used to be able to demand civil rights and access. It's always astounding to me that this isn't a more well-known fact that actually, the longest sit-in in American history is for disability rights movement.

**Keith:** So impressive.

**Maddie:** Because of all of this, Secretary Califano signed the legislation after the sit-in, so it was a success.

**Keith:** It was a success, for sure. As you mentioned the success in so many other ways, different underserved populations working together. It's such a beautiful thing to go back and think about and relive their accomplishments such as this. It's fascinating. Speaking of accomplishments, of course, Judy Heumann had many.

Just to run through them, Maddie, you already mentioned the Center for Independent Living. She started the Berkeley Center for Independent Living, which helped to launch that independent living movement, and the whole CIL or Center for Independent Living network, not just in America but globally.

In 1983, she co-founded the World Institute on Disability with also equally famous Ed Roberts and Joan Leon. From '93 to 2001, she was assistant secretary for the Office of Special Education and Rehabilitative Services.

That's under the Department of Education. That was during the Clinton administration. That's a huge impact there. After that, change of administration, she moved on in 2002. She became the first advisor on disability and development for the World Bank and did that until 2006.

In 2010, President Obama appointed her as the first Special Advisor for National Disability Rights at the US Department of State, and she held that position through 2017. As I'm going through this, it's amazing. So many times we've said, oh, the first, the first, the first.

**Maddie:** That's what I was thinking. That's what I was going to say.

**Keith:** Just trailblazing throughout her life.

**Maddie:** What's really notable about Judy, is that she demanded and was starting to expect these positions to exist that didn't exist before. Like you said, first special advisor or first advisor on

disability. Those are positions that exist today, and those are not even a decade or two decades old.

It's really, really crucial that disability remains in the forefront of our political mindsets, and disabled people are thoroughly involved in government and politics, to ensure that the things that she experienced growing up, don't continue to happen.

**Keith:** For sure. In 2020, she published her memoir "Being Heumann -- An Unrepentant Memoir of a Disability Rights Activist." That was a major publication in the world of disability rights for sure, so much so that a year later, she wrote a young adult version called "Rolling Warrior." Not long after, a studio agreed to a movie adaptation of "Being Heumann."

**Maddie:** I'm so excited.

**Keith:** I know, I know. It's great. Last I checked it's still under development by Ali Stroker, the first actress on Broadway that uses a wheelchair. She is set to play the lead. That's incredible.

**Maddie:** Ali Stroker herself is a trailblazer.

**Keith:** That's a story of its own. For sure. That's great. I can't wait for that. You already mentioned the Crip Camp -- A Disability Revolution, that came out in 2020. She also hosted her own podcast, "The Human Perspective." That's a very successful podcast in the disability space for sure. Some wonderful guests and great stories on there.

**Maddie:** Check that out if you haven't. A valid and common criticism of the disability rights movement is that it was primarily white, and physically disabled-centered, which again is valid. I will say that this does not negate anything that she's done. It's still very important, things that she's done.

I will say that this podcast does make a really big effort to bring other communities, other marginalized communities to the forefront, to be able to tell their stories and talk about what disability means in their communities, and what living at different intersections looks like, which I think is a continued story that needs to be told.

The one that Judy acknowledges very openly all the time, that the disability rights movement was whitewashed, even in its retelling of history. She does a really wonderful job of being able to go back and give other communities the recognition that they need and deserve and to continue to tell those stories.

**Keith:** That's a great point. You're right. She has made that effort and has been pretty successful at it. There really are amazing guests on there from so many different backgrounds and walks of life.

**Maddie:** Definitely.

**Keith:** Judy obviously had a great sense of humor. She was on a couple of Comedy Central shows. Her story was told in a show called Drunk History on Comedy Central and was portrayed by Ali Stroker.

That's pretty cool. She was a guest on The Daily Show with Trevor Noah, as part of her book promotion, also in 2020. Just a down-to-earth, funny, personable, individual, yet so powerful, and so influential.

**Maddie:** There's this really great quote from Judy from Crip Camp, where she says that she wants to see feisty disabled people change the world.

**Keith:** Such a short and sweet quote. I love that. It's a good choice of words too. Fiesty.

**Maddie:** How we started, we wanted to give Judy her flowers now that she's become a disabled ancestor and has passed on, and really acknowledge and just attribute so much of disability rights advancement to her existence, honestly.

There's plenty, plenty more that we weren't able to include because she truly is such an accomplished and impactful individual. Unfortunately, Judy passed on March 4th, and they had services for her this past Wednesday when we recorded, which is March 8th.

They live streamed it so a lot of folks for distance, or safety, or access needs, or whatever it might be, could still join, and honor, and appreciate her, and pay respects to her. You can watch it if you missed the services. They did record it.

They recorded the live stream, so you are able to go back and tune in if you'd like. A lot of folks I've seen online in the disability community said it was really beautiful and definitely paid good tribute to her life. I caught the beginning of it, but I got to go back and watch the rest of it.

**Keith:** I need to watch it too. There's a link on her website, [judithheumann.com](http://judithheumann.com). It's on the home page. There's a link to it, so you can find it really quickly.

**Maddie:** That's great. We really are truly indebted to Judy, and everything that she's done for the disability community and communities, and people in and across America and the world frankly. We thank you, Judy.

We'll definitely miss you, and your presence, and your wit, and your advocacy. It definitely was a huge loss for the disability community. We'll definitely miss you.

**Keith:** For sure. We'll definitely go back and watch the live stream, and learn more about her, read her memoir. If you haven't before, watch Crip Camp. There's a lot of great information out there for sure.

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**Maddie:** Thanks, everyone.

**Keith:** Thanks for listening.

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