Episode 14: Know Your Rights – A Conversation with Judith Heumann

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Mindy Henderson: Welcome to the Quest podcast proudly presented by the Muscular Dystrophy Association. I'm your host, Mindy Henderson. Together we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them. We are here for you, to educate and inform, to demystify, to inspire and at times to entertain. Thanks for joining. Now, let's get started.

Mindy Henderson: Today's guest has so many accomplishments and credentials, I almost don't know where to begin. This is going to take a minute so bear with me. Judy Heumann is a lifelong advocate for the rights of disabled people and is often referred to as the MLK of the disability, civil rights movement. She constructed polio as a child in Brooklyn and began to use a wheelchair for her mobility. She was denied the right to attend school because she was considered and get this, a fire hazard at the age of five.

Mindy Henderson: Her parents played a strong role in fighting for her rights as a child, but Judy soon determined that she, working in collaboration with other disabled people, contemplate an advocacy role due to continuous discrimination. She has played a role in the development and the implementation of major legislation, including the IDEA section 504, the Americans with Disabilities Act and the convention of the rights of persons with disabilities.

Mindy Henderson: Judy has published several books, has been featured in numerous documentaries, including the acclaimed Crip Camp. From 1993 to 2001, Judy served in the Clinton administration as the assistant secretary for the office of special education and rehabilitative services in the department of education. And during his presidency, president Obama appointed Judy as the first special advisor for international disability rights at the US Department of State.

Mindy Henderson: She has received numerous awards and has been awarded numerous honorary doctorates. If you can believe it, I haven't even scratched the surface. Judy, thank you so much for joining me today.

Judy Heumann: You're very, very welcome.

Mindy Henderson: Well, I'm going to jump in. I'm so excited to talk to you. I have a 1000 questions for you. Like I said, you were a prominent part of the documentary Crip Camp. And first of all, if anyone out there has not seen it, you should. I've watched it multiple times. It's fantastic. And I thought it did a really good job of telling the story of how you got into advocacy work, but none of us are born as advocates. How did you learn to be an advocate?

Judy Heumann: I can ask you the same question and we can have a little discussion on this.

Mindy Henderson: Sure thing.

Judy Heumann: I think I learned to become an advocate for a couple of reasons. One is my parents learned to become advocates. I was learning at a very young age, although of course, I didn't really understand where advocacy nor do they necessarily use them themselves. But I was learning that if there was a problem you had to fight for the solution. Not always fight, but in case of they deny the right to go to school and other issues that I was facing. And my parents were learning about over the years that other families who had kids with disabilities were facing. So we were learning about advocacy from some of our parents. And then we were recognizing that as we were getting older, we didn't want adults speaking for us.

Judy Heumann: And I think also the generation that I grew up in was when the civil rights movement, because of media and television people were learning more about it. And I, and my friends were seeing how other groups of people were addressing discrimination and that there were goals that people wanted to achieve. The right to vote, the right to get on a bus and sit where you wanted to sit, the right to earn an equal wage. All those things were also relevant to those of us who had disabilities, but the other issues we didn't see other groups really talking about disability.

Judy Heumann: They didn't really... Well, they were non-disabled people who didn't really understand disability. It was very important for us to begin to look at the barriers that we were facing. And I think what you see in Crip Camp and in the two books about me, one for adults and one for young adults Being Heumann and Rolling Warrior. You see that coming together, coming up with solutions and trying it. Figuring out, okay, we want to change this, how do we do it? Who do we do it with?

Judy Heumann: We had to learn all types of things like how are laws made? Do we know our city council representatives? Do we know our county people? Do we know our state people? Do we know our federal people? There was so much to learn, but I think we learned little by little, when we were at college and there were no disabled student service offices. How we could get a disabled student service office set up. And we were learning by doing and realizing that we needed to be able to both tell our stories and why these things were important to talk about discrimination, which really, I think you, Mindy and your listeners know that in the area of disability, people don't always call it discrimination when we're being denied a job because of our disability.

Judy Heumann: When we're being denied access to something or, but what was important and still is important is that as individual people and there's groups of people both disabled and nondisabled being able really to speak up and out about why discrimination is wrong and what else needs to be happening. And we were learning that from the civil rights movement, from the women's rights movement and the anti-war movement and the growing movement for older people. The Gray Panthers was another group that I was the one involved with.

Mindy Henderson: Okay, great. So when all of this sort of unfolded, did it happen naturally and organically a step at a time, or did you really have goals in mind and did you set out initially to make these grand broad sweeping changes in the world?

Judy Heumann: No. I mean, certainly when we were teenagers, we didn't have a strategic plan. If anything, I think about it as being in a candy store. There are 50 candies, what do you select first? How much money do you have? And because the problems and discrimination that we were facing and in many cases still are, are varied. And people would have different areas of interest and I think that was something that has become more critical as we move forward.

Judy Heumann: So in the beginning, in my beginning, because I don't want to say that this movement started just with us, but it started in the '30s. It started in the 1700, it started in many ways, different ways, different issues. But when I was denied my right to teach and we set up this organization called Disabled In Action. And when I sued the board of Ed and got my license, DIA was really... It still exists in New York.

Judy Heumann: A DIA became across disability and disability led organization, which was very different for that time because there were many groups like MDA and United Cerebral Palsy and others that really only focused on particular groups. And in many cases they were focusing on the cure, they weren't focusing on the day to day experiences. One of the people in DIA was a guy named Jimmy Lynch and he had muscular dystrophy and he hated the telethon. He and another friend and were leading work that we were doing through DIA, which was no funded. We had no money, but we had advocacy interest in drives.

Judy Heumann: Jimmy and a friend of his staged a hunger strike outside of the telethon in New York. And we were completely inexperienced, but looking at ways that we can help amplify their message and their message was and we supported it, that telethons did not project the image that we and disabled people, not just people with muscular dystrophy wanted to be portrayed.

Judy Heumann: It was the same thing for the UCP telethon where in both cases it was talking about the tragedy of our lives. And that was also something that issue was resonating more and more across the country. We would kind of sarcastically joke, go out and try to get a job the day after one of these telethons had been on and who would hire you when they really just, at that point were really looking at the various disabilities in a tragic way. Nobody was talking about not doing medical research, but people were talking about, we need to go to school, we need to be able to get across the street. We need to be able to get on a bus. We need to be able to get a job. We need accommodations. We need home and community based services, various things like that.

Judy Heumann: So I think these were themes that were beginning, I don't want to say emerge, but we were beginning to articulate and feel comfortable in defining the message that we wanted people to hear at the same time that we were beginning to look at ways to work with other groups that were mainly nondisabled run groups who knew more about laws and how they were made getting involved with them so we could also have influence on multiple levels of government.

Mindy Henderson: Mm-hmm (affirmative). Interesting. Yeah. And the world obviously, has evolved a lot and there's still a ton of work to do. And I'm so proud to be a part of the work that's happening today. And MDA's mission today is really to empower the community. And several of their biggest pillars are inclusion and independence and those sorts of things. And it's so exciting to see those changes happen. But knowing that like I said, there's still a lot of work to be done. And there are so many nuts and bolts to advocacy work. And a lot of what you said resonated with me and thinking about my own life, I think I haven't necessarily set out to be an advocate. It's something that's just sort of been a natural progression.

Mindy Henderson: And like you said earlier a problem presents itself. I also got to fight to go to kindergarten and mainstream elementary school with all of the other kids. They wanted to pigeonhole me into special ed just because I sat down all the time. I think that for me also, as the problems came up, you solve the problems and over time you improve the situation and you strengthen your voice and you become better and better at advocating for what you need. But there are people listening right now who have maybe ambitions in a certain area, I don't know, maybe they've got a special interest in a particular area of disability rights. Where do you begin? What does that organizational process look like to step into advocacy if you're doing it with some intention?

Judy Heumann: I mean, I think Mindy, it depends on your age. You were in kindergarten, I always in kindergarten. I presume that your parents intervened.

Mindy Henderson: They did.

Judy Heumann: Exactly. And what year was this?

Mindy Henderson: 1978.

Judy Heumann: Okay. So 1978, three years after the IDEA and to my math, six years after 504. So the laws were in place, beginning to be in place. Whereas in 1952 or '53, when my mother took me to school, there were no laws. So your parents were able in a couple of levels to argue for what you needed. One was, I don't know if they knew about the law, but that... Do you know if they knew about the law?

Mindy Henderson: No, I don't know, actually. I'm sure they learned what I was entitled to legally along the way. I don't know if they went into it knowing that.

Judy Heumann: That would be an interesting thing to find out.

Mindy Henderson: It would.

Judy Heumann: Because people have rights, but we don't necessarily know how to use them or we don't want to be litigious. So I'm sure your parents like mine came in arguing for what they felt you would benefit from and they won, right?

Mindy Henderson: Yes.

Judy Heumann: Now, that I think is a clear example. They didn't know what advocacy was. They probably weren't an advocate before you came into the family and there were probably other incidences before you were five where they had to advocate and whether or not you called it advocating speaking up on your behalf. If people felt, well, Mindy or Judy can't do this, that, or the other thing they would say, "Yes, they can. They may do it differently but yes they can."

Judy Heumann: Not supporting inclusion before there were any term. So I think what I want to say to people about advocacy is you start at the beginning and it's your beginning. So you may not belong to any organizations. I mean, I think if you're listening to this podcast, obviously you are doing something where you're involved with MDA. And then of course, there are many subdivisions now of people who have muscular dystrophy, which didn't really exist when I was growing up.

Judy Heumann: SMA as a group, there were people at SMA for a long, long time, but it's special, not special, but it's a group of people who have aligned together not exclusively. But for me, I think about advocacy as something where if you have a disability, there is an issue for you where you feel there's a problem that either you are facing or you and other people are facing where you want to make a difference. And getting your voice and being able to feel like, what do I want to do? What role do I want to play? Are there other groups that I could be joining where I could be learning?

Judy Heumann: Sometimes people want to learn before they do. Now, they know their own experience, but they may want to know someone else's experience to see what they've done. So the discussion that you and I were just having about when you were five years old and your parents took you to school and my parents took me to school that can be an important discussion for other parents. Who can say I'm trying to get my kid into a regular classroom and they're saying, "No, and I don't agree with them, what do I do?" So people like you and your parents can be there to help support them as they learn to become advocates.

Judy Heumann: But it can also be something I think about incidences over the course of my life. So I was in New York, in the early '70s with a couple of other people in wheelchairs, in Manhattan. And we went into a Chinese restaurant and the manager said that we had to leave because he didn't want us in the restaurant. And okay. So I hadn't prepared for that. I hadn't trained for it.

Mindy Henderson: No, you don't expect that.

Judy Heumann: But because of what I'd been doing over the year, I realized that I didn't have to say yes, I didn't have to leave. And on the spot, like you and thousands of us do, I said, "No, we're not leaving. If you want us to leave, call the police." And I don't know where that came from. I never said that to anybody before, but that was my advocacy coming out and realizing that, no, why was he telling us to leave?

Judy Heumann: So there was this conflict to want to eat there now and give him our money. But we did because there was no way we were going to leave. And he didn't call the police, but there are so many incidents in our lives where little things like that are not little and they can really have a big impact, both on your feeling empowered by being able to directly address something that's wrong. Advocacy and as a disabled person, our advocacy doesn't need just to remain in the area of disability. It can be dealing with disability and race and gender and religion, issues like the environment and the role that we should be playing in addressing pollution and global warming, things of that nature.

Judy Heumann: So I think looking at your own life, looking at the changes that you want to continue to work on, finding an area that you want to engage more and it may be the area that you're studying. There may be research that you want to do on disability where others don't think it's important, but you know that it is. So it can be so many things. And I think Mindy we don't know each other, but I can project that given the podcast that you do and your networking, that if things are coming up, you'll call other people. You'll know other people to call on a subject, you'll be able to help generate interest and ideas.

Judy Heumann: And to me, 504 and the ADA and IDEA as examples, all were pieces of legislation and regulation development that we needed to be organized around. We needed to be strategic and the UN convention, the rights of persons with disabilities. But getting people to that first step of being able to say, "No, I don't accept second class citizenship. No, I don't accept people looking at me as being inferior." And being able to bring yourself forward, that's advocacy, it's the beginning of respect for yourself and articulating it.

Mindy Henderson: Absolutely. Knowing your worth.

Judy Heumann: Exactly. Fully being in your worth.

Mindy Henderson: Absolutely. Yeah. Gosh, there's so much that you just said that I would love to dive into because like you said, it starts with believing in your worth and knowing your value and being willing to fight for it, for lack of a better term. But then you also talked about how our parents did what they did and then along is going to come another set of parents with the same problem. And it's about sharing our stories, I think too, and really being willing to talk to each other and share what we've struggled with, how we overcame it, how we solved the problems that we solved almost as a service to our neighbors and our community.

Judy Heumann: I think many of the things that we work on that we hope have been resolved likely still haven't been resolved. I think we still hear stories today of families who are trying to get their child into an integrated classroom in 2022. And their child may not just have a physical disability. They may have a physical disability plus something else. But that doesn't mean... Or they don't have a physical disability and they just have whatever the other disability is, but they have the same rights under the law to be educated in the least restrictive environment.

Judy Heumann: Laws are wonderful. We need them, they need to be enforced, but we always need to recognize that the laws are as good... Well, both at the law itself, but also by people knowing about what the laws do and don't require by helping people learn about how to use these laws in different situations. And also, I think now we're just narrowly discussing education, but looking at what universities are teaching undergraduate and graduate students in education. And whether or not learning about inclusion of disabled students in classroom is something they're really learning about. And looking at ways of preventing discrimination, preventing problems.

Mindy Henderson: Right. Agreed, agreed. So this is such good stuff. I want to get into some other topics. Let's talk about legislation for just a second, because that is a very specific part of advocacy and the work that you've done, but changing legislation can be really slow going. How do you personally stay patient when things move so slow? Because it's frustrating. You look at something like air travel and me personally, I just want people to do the right thing. And sometimes it feels as simple as that, but clearly it's not. To make legislative change how do you stay patient when it's frustrating how long things take to do?

Judy Heumann: I mean, I think airline travel is a great example because we see that many of the laws that have been in place now for 30, 40, 50 years are beginning to make changes that are allowing disabled individuals to go to school, graduate from school, get jobs, travel being something that people may be doing for work or for pleasure. And yet airline travel in so many ways for disabled people is only getting worse. Not to say, it's not getting worse for everyone given certain things going on. But I would say that some of our issues are different and unique. The ability to get transferred onto a seat, to get on the plane. The ability to have confidence that your wheelchair is going to be put under the plane and not be damaged. People really don't understand the implications when someone's wheelchair is broken.

Judy Heumann: And there is work that's being done on this. But my personal feeling is we've not ramped up what we're trying to do and that's not disparaging any of the wonderful people who've been working on this really hard. I think part of the issue is that not enough people are traveling who use wheelchairs or other forms of technology and they don't know what their rights are under the Air Carrier Access Act, which is not strong enough because you can't litigate, but nonetheless it's there. We don't necessarily complain.

Judy Heumann: And in too many cases, I think including myself, deciding whether you're going to get out on an airplane is something that you think twice about. And it's not just because of COVID.

Mindy Henderson: No.

Judy Heumann: It's because of the number of stories where we're hearing that wheelchairs are broken.

Mindy Henderson: Yeah. Well, and for me I haven't been on a plane in 10 or 12 years.

Judy Heumann: Why?

Mindy Henderson: Because frankly, flying is a deterrent for me. The whole process of being a person who uses a wheelchair and it's everything from the dangerous to dehumanizing to risky because like you said, to be transferred onto the aisle chair and into a seat and all of that you're being handled by strangers who aren't aware of how to, or not to move you. I've been injured before getting transferred on a plane. I know the damage that happens to other people's wheelchairs. And I know that the airlines have processes and things in place to repair your chair, but that doesn't do you a lot of good in the next 24 hours of your life. It's akin to breaking a person's legs.

Mindy Henderson: For all of those reasons, I just haven't been willing and it's been a personal choice, but I haven't been willing to put myself through all of that and get on a plane, which is a shame because like you said, there probably aren't as many people who use wheelchairs today traveling. They don't necessarily know what the demand could be, but I think the demand is huge. And I think that they would see a lot more people traveling if they could be treated in a human way.

Judy Heumann: Yeah. Well, I think the airline travel issue is important, in addition to what you're saying. It really indicates how we restrict our lives more than other people have to. Because the wheelchair that I use is not made anymore. And I've tried to get other wheelchairs and thus have not found any that work for me. So I mean, until COVID, I traveled a lot and I did a lot with the airlines to try to prevent my chair from being broken. But even as much as I would be doing, like I went to Ecuador, they broke my wheelchair going down and they broke my wheelchair coming back...

Mindy Henderson: Oh my God.

Judy Heumann: Not major, major things. And then I went to Mississippi, they broke my wheelchair again. So I think we need to be letting our congressmen and women and our senators know that airline travel is important. And we want them to be addressing this issue. And Paralyzed Veterans of America is one of the organizations that's been doing a lot of work on airline travel with a coalition of disability rights organizations, including groups like the Disability Rights Education and Defense Fund. But I think we need to really ratchet this up because it limits our ability in so many ways. And I think the other issue is COVID has resulted in everybody being much more restricted in their ability to move around, but that's changing. And I don't want people to think that as disabled people, our desire is to stay at home.

Mindy Henderson: No. Goodness, no.

Judy Heumann: I think is the wrong message. Whether it's for education or for work or just doing things in the community an airline travel is something that is a part of what our society does.

Mindy Henderson: Yes. And honestly, I worked a corporate job in high tech for 20 years I've had a very, very successful career, but my ability to travel a little in an efficient and reliable way has definitely affected jobs that I've had or jobs that I've taken or not taken. And it's impacted the places that I would love to go that I haven't seen yet just because of the hassle of flying. So I hear what you're saying about contacting our legislators and that sort of thing, but is that enough? What do you think really needs to up and to move the needle on this issue?

Judy Heumann: Well, I think it's the work that PVA and these other groups are doing the hearings that were held last week. Today is April 7th. And the hearings were last week or the week before from the department of transportation. I think we shouldn't be quiet about it. And I think working together is very important. And I think also as you were saying and as I was saying, telling our personal stories. And there's so many things that we're working on, but I think airline travel for a percentage of the population is very important. And for us to be not only seeing the situation not get better, but actually seeing the situation getting worse is a problem.

Judy Heumann: And if I had the answer, answer, we wouldn't have the problem anymore. But as I said, I think the department of transportation needs to hold the airlines much more accountable. It's not just the reporting on the number of wheelchairs that are damaged. It's damages that need to be paid by the airlines and by their subcontractors. And if you travel and your wheelchair breaks, you do not have use their repair people. If you've got your own repair people, I never use their repair people. I only use my own repair people. And when I have a problem, I always file a complaint under the Air Carrier Access Act. Not that much that's necessarily done, but it's because we filed it, but...

Mindy Henderson: That becomes strengthened numbers, if everyone files every problem they ever have, it becomes harder to ignore.

Judy Heumann: One would hope. And I do believe that secretary Buttigieg is interested in this and Kelly Bucklin, who is now a special assistant in the department of transportation is a quadriplegic who used to head up the national council on independent living and he is certainly working on this. But I'll get you the information on who to contact, who's doing work on this then you can share it with your listeners.

Mindy Henderson: I will, I would love that. Thank you. Let's talk about employment for just a second because employment is still a big issue for the disabled community. And I'd heard a statistic last year, I think it was that something like 27% of the population of individuals with disabilities have positions in our workforce today, as opposed to 87% of the nondisabled world, which is staggering to me. What do you think the single biggest thing the corporate world needs to do to further DIA?

Judy Heumann: I don't think there's a single anything. But I believe that corporations big and small and nonprofits big and small need to really look at what is going on within their operation. And by that, I mean, how are they doing recruitment for positions? How are they training their human resource staff and they're hiring managers. Now, remember we can be talking about companies of 25 and more so there's big variation. But is there a bias within the organization that people who have certain kinds of disabilities cannot do a job just because they have X disability.

Judy Heumann: There're organization like Disability:IN and National Organization on Disability, and then at state and local levels that are looking at the issue of employment of disabled people and more and more disabled people who are working, who are discussing these issues. I think that changes are slowly coming about. We are seeing a little bit of progress being made in disabled people getting into the world of work. And I think another issue is as you know some disabled people are receiving benefits from the federal state government. And that those benefits have been pretty restrictive in relationship to the earning that you can have. How much you can be earning, how much you can be saving.

Judy Heumann: Those changes are slowly coming about, which are lifting some of these restrictions, which will also enable disabled people to be looking more proactively at getting work. So I think there are multiple things employers need to really on a regular basis be looking at what are they doing to address issues of biases on race, on gender, on sexual orientation, on disability. What are they doing to make these needed corrections so that the staff that have responsibility for outreach, for hiring, for management are making sure that they and their staff really are looking at, in this case, disabled people, finding people who meet the qualifications and making sure that the biases are being removed.

Judy Heumann: And the reason I mention groups like Disability:IN and National Organization on Disability and many others is that these groups bring people together on a regular basis. And these businesses are talking about what needs to happen. Some of them are doing more than talking and acting. But again, I think this requires those of us in the disability community to be speaking up and out when people are experiencing discrimination to seriously look at what they believe should be happening. Are they going to file a complaint? Are they going to go speak to the human resource people within the agency or the business?

Judy Heumann: But again, it's, I think being a part of a larger group of people who are knowledgeable about rights, some of them will be more knowledgeable about employment related issues. And I assume in the work that you're doing Mindy with a large number of followers, that you have people who have knowledge and expertise in a broad array of areas. I think allowing people to learn about the employment provisions in the various laws, what they require employers to be doing, those are all important things to know what your rights are.

Mindy Henderson: Absolutely. And yes, I definitely think that I'm hearing another theme over the course of listening to you talk of just making sure that we ourselves are educated and what we're entitled to, which is huge. What issues have your focus right now and how are you approaching them?

Judy Heumann: A lot of what I'm doing right now is speaking to many, many different groups. High school students, elementary school students, college students, businesses, religious groups, Crip Camp and Rolling Warriors and Being Heumann are the film and the books are things that people are seeing and reading or listening to put their own audio also. And in many cases, people have very basic questions. They're really learning about the disability community for the first time, including disabled people who in many cases are learning that there is a movement out there.

Judy Heumann: But I think there's some very exciting things that are happening, groups like the American Association of People with Disabilities, which has many different areas of emphasis, but one of them being in the area of voting rights. And I think voting is something that is so very important and pivotal. When we talk about issues of employment or education or transportation, we need elected members at the federal level, the state, local levels who understand who we are and see us as voters. It means we have to be educated people.

Judy Heumann: AAPD has a program called RevUp and they work in a number of states and RevUp is really working on... It's nonpartisan, but it's working to help disabled people understand things like how to register to vote. And when you're voting, if there's a problem what to do. And then also working with candidates from all political parties to get them to respond to questions so that we can be a more informed voter. And those are things that are going on at the local and state and federal level, but being more visible, more active, I think is very important.

Judy Heumann: And I think being critical, critically thinking. For me, some of the issues that I look at in a candidate relate to things like, what are their positions on healthcare? Did they support the ACA or did they not support the ACA? I supported the ACA because it gave people who weren't insured insurance. I know what people get in other countries and what we get in comparison to them. And I want people in this country to learn about how healthcare is provided in other countries and actually speak to other disabled people and find out. If you were to live in X country, what would your healthcare look like? Would you be getting your durable medical equipment? Would you have a high copays?

Judy Heumann: Could you be denied the right to get certain services because you didn't have insurance at all? These are things that we need to understand. And I think for me also, the environment is a big issue now. And I don't believe that disabled people yet are enough engaged in the issue of global warming. And we have a lot to be worried about because everything indicates and we've seen this, that preparation for disaster preparedness and what happens after a disaster, disabled people are not at the core of people's thinking, regardless of the amount of work we've been doing.

Judy Heumann: We want to prevent disasters. We don't want to look at only what to do in the event of a disaster. I think we need to look at the implication of global warming on things like breathing. And for some of us I had polio, but I had all three types of polio, one of which affects breathing. I am very concerned about what's going on with pollution on a personal level, as well as beyond. I think, think we need to include as a part of who we are, our disability in a way that enables us to move forward, living our lives the way we would like to.

Judy Heumann: And for me, it's reaching out and working with others. I work with a lot of different groups, I'm at a lot of different boards of directors, because I'm wanting to work with people who share some of my views and where I can be learning as well as adding. So continuing to speak up and out. And I think really also continuing to expand our movements so that those who have invisible disabilities as an example, see themselves as a part of the movement.

Judy Heumann: But I also think Mindy, you and I are getting older as is everybody else. And when I had polio, when I was 18 months old, obviously even as I got older, I didn't necessarily think about issues around aging. But we have a lot to offer the aging community because people who acquire disabilities as they're getting older, should be looking to us for answers to questions, but also should be listening to us in relationship to why is it important to have new housing stock, which is accessible?

Judy Heumann: Why is home and community based services so important? How can we more effectively work together as an intergenerational community of disabled individuals? So we've done a lot and we have a lot further to go. And I think one of the other important changes is how the disability movement now is really a global movement and how to continue to work with groups, not just within our communities, but outside the United States also.

Mindy Henderson: Yes. Absolutely. Gosh, so well said. I think that may be a really good note to leave things on so much wisdom. I can't thank you enough for being here. So Judy, you have all kinds of things where people can look you up. I'm going to put all of your information in the show notes so people can find you, connect with you. You have a great newsletter. Your podcast is fantastic, your books, you have a t-shirt available on your website. Would you tell us about the t-shirt?

Judy Heumann: Yes. The t-shirt, a group came to us. I want to see feisty disabled people change the world. And this organization called Bonfire reached out to us last year about working with us on designing this t-shirt. And we are giving the profits of the t-shirt to the American Association of People with Disabilities and the Disability Rights Education and Defense Fund, because they're doing national in some cases, global advocacy, but it's a fun t-shirt.

Judy Heumann: Also last year, a company in Minnesota called Lark, L-A-R-K unbeknownst to me, made a Judy doll and it's a wooden toy. It's a wheelchair and it's got a string on it. And when you pull the string, it moves and the arms move and push the wheels. They have a Judy doll and I believe they have a Mike doll and he's in a wheelchair and it's a great little company. So if you're looking for presents to buy for kids five and under it's Lark, L-A-R-K.

Mindy Henderson: That's amazing. I'll find it and make sure that's in the show notes, we'll make sure that people can sign up for your newsletter and stay informed on all of the wonderful things that you do. Do you have any parting advice or words that you'd like to leave our listeners with?

Judy Heumann: I mean, I really thank you Mindy for the work that you're doing and for all the people that you're working with around the country and being able to participate with others and raise our voices is what this movement is all about. Coming from behind the shadows, being proud of who we are and demanding what is ours by right. I think that's all important, really not for ourselves only, but for those younger and older than ourselves.

Mindy Henderson: Very well said. Judy, thank you so much for being here with me today. I really appreciate it.

Judy Heumann: I appreciate your asking me. Thank you everybody. Thank you.

Mindy Henderson: Thank you for listening. For more information about the guests you heard from today, go check them out at mda.org/podcast. And to learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved and to subscribe to Quest magazine or to Quest newsletter, please go to mda.org/quest.

Mindy Henderson: If you enjoyed this episode, we'd be grateful if you'd leave a review, go ahead and hit that subscribe button so we can keep bringing you great content and maybe share it with a friend or two. Thanks everyone until next time go be the light we all need in this world.

(music playing)