



**Hosts:**

Holly Carmichael  
Michael Murray

**Guest:**

Judy Heumann

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**Introduction:**

A Garrison is a safe place where an army gathers. In the same way, the Disability Garrison Podcast is a place for the army of disability rights advocates to gather and discuss complex issues. We are unafraid to identify problems in our world and have difficult conversations about them. But we are not just here to complain. We spend our time brainstorming solutions with generals in the disability rights movement. Together, we take action to make positive change and lead the fight for justice and equality.

**Holly Carmichael:**

My name is Holly Carmichael.

**Michael Murray:**

My name is Michael Murray. This is the Disability Garrison.

**Holly Carmichael:**

Imagine for a moment that you're taking a shower or bath. Do you recall the last time you did that? Maybe it was earlier today or yesterday or even last week. But I want you to remember what it felt like to get undressed and feel the water over your body, wash your hair.

And I want you to think about for a moment what it would be like if you needed help with this really intimate care need and imagine if you could what it might be like if the person helping you was somebody you didn't like or even somebody who didn't like you or maybe even just somebody who is indifferent to the task and it was just part of their everyday job like you or I might load the dishwasher.

Today we're going to be talking about personal assistance and how important choice and control over those personal assistance services and supports really is.

**Michael Murray:**

The act of helping another human being with these basic needs has existed really since human beings have been around on the planet. But the recognition of this need and the recognition that it should be

something that we should be able to look to and have a safety net for has only really been around since the last century. And so personal assistance services began to gain real traction in the 1970s with the creation of the Berkeley Center for Independent Living in California.

In 1983, there was a formalized home and community-based services (HCBS) which was first available when Congress gave states the option to receive a waiver of Medicaid rules governing institutional care. This made it easier for millions of people to receive care in their own homes and communities.

**Holly Carmichael:**

But still today in 2021, congregate settings like nursing homes and state institutions are in use that limit a person's choice and control. You don't know when you're going to get to take a shower or who will help you with that. And in our Medicaid program, it's an entitlement to receive services in these institutions but not in your own home or community.

There are waivers, as Michael mentioned, but there are almost a million people with disabilities on waiting lists to access these critical services. They're underfunded. There's a lack of knowledge, and fears about fraud and abuse prevent these services from being used more despite their improved outcomes and lower costs. Personal assistance is so critical, and it's limited even today.

At this year's Paralympic games, Becca Meyers had to withdraw from competition after the committee denied her request to bring her own personal care assistant, somebody she chose. They told her. No, she needed to use the one personal care assistant that was assigned to assist all 34 of the swimmers that were competing.

**Michael Murray:**

And that's what we're going to address today. This is what we want to talk about. How do we ensure that everyone who needs these services has access to them in the community of their choice? So let's jump into our interview.

I am so excited, Disability Garrison Podcast. And we have an incredible guest with us here today, a dear friend of mine, Judy Heumann.

**Holly Carmichael:**

An amazingly incredible guest. I am honored and thrilled to be in her presence. I can't wait for our listeners to hear what she has to say.

**Michael Murray:**

Yeah. Tell us about Judy.

**Holly Carmichael:**

Judy, Judy. Well, this will not do her justice, this intro. But Judy Heumann, for those of you who do not know her, is an internationally recognized leader in disability rights. When she was 18 months old, she

contracted polio, and her parents fought for her rights, taught her to be an advocate for herself. Little did they know she would go on to spark a revolution. She graduated from Long Island University in 1969, received her Master's from University of California-Berkeley in '75.

Just a few of her amazing accomplishments include co-founding Disabled in Action as well as the World Institute on Disability. She served as the very first special advisor for international disability rights at the U.S. Department of State, appointed by Barack Obama, President Barack Obama. She also won an award for her role in the Oscar-nominated Crip Camp at the Critics Choice Documentary Awards. And if you haven't seen it, you got to see it.

She was the most compelling living subject of a documentary. Her advocacy efforts have reached millions, and she has paved the way and really led this movement. She played a huge role in the development and implementation of major legislation including IDEA Section 504, the ADA, Americans with Disabilities Act.

She has two great books, *Being Human: An Unrepentant Memoir of a Disability Rights Activist* and most recently converted this into a youth novel, again, just continuing her spark for young kids, *Rolling Warrior: The Incredible, Sometimes Awkward, True Story of a Rebel Girl on Wheels Who Helped Spark a Revolution*. We are so honored to have this icon talking with us today.

**Judy Heumann:**

So let me thank you both for inviting me, and let me always say a couple things. I would not be where I am today if it wasn't for all the people that I've worked with over my life. Nobody does anything by themselves, and I think the disability rights was the perfect example. And both of the books, *Being Human* and *Rolling Warrior*, I wrote in conjunction with a woman named Kristen Joiner. And so I think my life really speaks to the issue of personal assistance.

Personal assistance for me is the ability to work with individuals who can help me do basic things like get up in the morning, bathe, get dressed, get the bed made, make my breakfast, help me with lunch if I need it and dinner, and can help me do those things which I can't do myself. I think it's a real model for all of the work that we do in the disability rights movement. It's the ability to work with other people in a collaborative way.

**Michael Murray:**

Yeah, I love that. And for some of our listeners, they may not realize that personal assistance is different than let's say going to a congregate setting or a nursing home. And can you speak to what that looks like and how that's different?

**Judy Heumann:**

So I would say that there are significant differences. I am involved in hiring the people who work for me. I also pay my workers directly. Now there are various models that people use, but for me, what's very important is the ability to define what it is that I need and to be able to look for people who I can work

well with and they can work well with me. And when you live in a more segregated environment, you have little to no ability to be involved with either the hiring of the people that are going to work for you and not necessarily be able to make the decisions which I and hundreds of thousands of other people are able to do. What time do I want to get up in the morning? What do I want to be eating? What do I want to be wearing? What don't I want to be doing? These are all very critical issues. And in segregated environments, the ability to do that is just not in the framework of what should happen.

**Michael Murray:**

Yeah, yeah. 100%. And I think that it really speaks to independent living and the independent living movement that you helped spark. And looking at your history and reading some of the books that you've done, thinking about your time at the University of California at Berkeley and the spark that started the independent living movement there, I'd love for you to speak about that and speak about what personal assistance looked like at that time.

**Judy Heumann:**

So I grew up in Brooklyn, and I was a teacher. And I needed to go to graduate school, and I was originally going to go to Columbia University. Then I got a call from a gentleman named Ed Roberts who told me about this program in California called The Berkeley Center for Independent Living. And one of the components of that program was personal assistance. So CIL would interview people who are interested in being personal assistants. If they seemed like they were competent and they didn't have any background problems, then you could as a disabled person go in and get a list of people. And I would interview people and select from that list. If not, I would look for other people. So when Ed Roberts called me, I explained to him that I used personal assistance.

And one of the reasons I actually did my undergraduate work and one of the reasons I studied at Long Island University in Brooklyn was because I lived in a dorm but I was near my family so that if there was an issue with personal assistants, my family could back up. But obviously, going out to California where I had no family at all, one of the main issues I had to think about was what was I going to do, how was I going to get personal assistance? And so Ed explained to me that there was a program in California called the In-Home Supportive Services Program. I met the income eligibility at that time.

So I moved to California to go to graduate school at Berkeley, got onto the In-Home Supportive Services Program in California. And then I was able to use the lists that CIL had or find other people. And I also met many other disabled people in Berkeley who had disabilities more significant than my own who were also using personal assistance. And it was great because we were able to speak to each other, learn from each other, talk with each other about ways of interviewing and helping to ensure that you were looking for someone and finding someone who could best meet your needs and best for them.

**Holly Carmichael:**

Yeah. Just simply amazing. I want to ask you a little bit about, because you played such a pivotal role in the passage of 504, The Rehabilitation Act, which really was a foundation for disability rights in our country. And it was the longest sit-in in a federal building in the United States history. And so I'm

curious. What was it like being in that building? How did personal assistance come into play? What was it like inside? I wish I was there.

**Judy Heumann:**

Yeah. I think a lot of people wish they were there. I think there were many things going on in the building, personal assistance services being one of them but another area was sign language interpreters because there were a number of deaf people there. And obviously, the deaf people could very effectively speak to each other because they knew sign language, but communicating with hearing people who had disabilities or not was a different issue. So what was going on in the building was really looking at what people's needs were and working on addressing them.

So there were some people who were part of the demonstrations who as a profession were personal assistants, and then there were other people who were chipping in and helping out. So it wasn't like being at home where a person that you knew was coming at a certain time and then somebody would come at another time, all arranged by you. So really it was we worked with people who were in the building, and we made it work. And I think, again, it wasn't ideal, but we did make it work because there were a lot of people who were participating who also maybe had invisible disabilities that were able to help with personal assistance. So we were all there for one reason.

That was to get the 504 Regulations signed in the form that they were when we took over the federal building. And I need to remind people that there were demonstrations at that time in the nine regions for the federal government. And ours was the longest, and I think it really, why was the Bay Area the longest? I think it's because more had been going on in the area of independent living at that time. The first CIL had started. Ed Roberts who had been a director and one of the founders of the Berkeley Center became the director of the Department of Rehabilitation. And then he used money from his budget to set up 10 centers for independent living in California, a number of them in the Bay Area, San Francisco Bay Area. So it was a very fortuitous experience.

And I think personal assistance was one of the pivotal issues that we needed to address. And because there was such commitment in the Bay Area for getting the 504 Regulations signed, we were able to do it.

**Michael Murray:**

Watching the videos from those sit-ins, it was my introduction to the disability civil rights movement. Made me proud of my disability. And there are some lines that you have that just still get me fired up. But one of the lines, and it really pertains to our topic today around personal assistance, was when one of the panelists who had come to try to get you guys to leave the building was like, can I get up and go to the bathroom? And somebody was like, actually, no, welcome to our world. We can't find bathrooms. We don't have the support that we need. And it really leads into your other work because you've never stopped fighting for this.

Some of our listeners will know that in 2017, the EEOC, the Equal Employment Opportunity Commission, passed an affirmative action obligation that requires the federal government to pay for personal assistance services, not just for work related things but for going to the bathroom or getting lunch while you're at work, these other things that are actually really important.

**Judy Heumann:**

So let me be clear on this because it's very important. So what we were able to do with what's called Section 501 Regulations was to obligate the government to provide services for employees of the government who in order to do things like work might need assistance in getting their coat on and off, getting their food, eating their food, going to the bathroom. And so they don't pay for that service for you to get to work or when you get home from work.

So that's what I think is important to understand, that there was a lot of work that went on because that was absolutely something that wasn't clear under Section 501. And I think this is a very important change in the 501 Regulations, that, as you said, were issued by the Equal Employment Opportunities Commission.

**Michael Murray:**

Absolutely.

**Judy Heumann:**

Because there have been too many disabled people who either are dehydrating themselves because they need help going to the bathroom or they're having to bring somebody from the outside in to help them go to the bathroom. And so this change which came about, I believe it was in 2016, at any rate, it was very, very important and still is very important.

**Michael Murray:**

And I think that you and I worked alongside this, but what folks may not know is that you paved the way for people to understand a new way of looking at this when you were at the Department of Education.

And I just wonder if you could talk a little bit to our listeners, especially those who may need personal assistance in the workplace, about how to talk to their employers about this. Maybe they're not in the federal government. How can we start to make an impact in some of these other arenas?

**Judy Heumann:**

I mean I think one really important issue is, as we've been discussing, that the federal government finally has cleared this up. And so that's like a major issue because then it really is an example for the private sector. Now there certainly are companies in the private sector that are providing this kind of support for their employees. But my presumption is that it's more not the norm in part because disabled people who need this service in order to do their jobs may be reluctant to ask about it. Because if it isn't something which is freely being given, and there aren't going to be that many people working in a company who need this kind of assistance.

When I worked with CIL and when I worked with the World Institute on Disability there, our goal was to hire as many qualified disabled people as possible, and there were numbers of people who needed assistance. The same thing with many other disabled run organizations.

But you don't expect to have huge numbers of people, not because of discrimination but because of the size of the population and the variety of disabled people. So I think what's important is that we remove the stigma of needing assistance, doing things like getting your coat on and off, feeding someone, helping someone go to the bathroom. These are things that people don't like to talk about, but when I joke around and say, okay, we'll take all the bathrooms out of a building and then go deal with it, people are like, you're crazy.

But it's like, well, this is really what it is you're asking us to do because if I need assistance going to the bathroom and I can't get it, it's just like there is no bathroom. So then you learn to dehydrate yourself and you learn to do all the things that we've had to do. But I think on a positive note, people are slowly getting a better understanding of what personal assistance service is, and I think we're seeing parents who have children who need assistance becoming much more engaged in this discussion and likewise adults with disabilities who are being less closeted so to speak about needing these kinds of supports.

**Holly Carmichael:**

Yeah.

**Judy Heumann:**

But it's still really very small because of the way people react. It's like something that everybody does multiple times a day but nobody wants to talk about it.

**Michael Murray:**

Yeah. And I think it's important. And in my fight around employment, I want employers to step up to the plate and be a part of this and be a part of this conversation. And so I just really admire you for that. We've got one last question, Judy.

**Holly Carmichael:**

Yes. Well, as you've been called the mother of the disability rights movement and—

**Judy Heumann:**

I'm one of the oldest people.

**Holly Carmichael:**

Well, mothers give advice. And what I want to know is what's your advice for what's next? You talked about choice and in control of your life to live independently and how personal assistance plays such a crucial role in that. What's next? What would you say to this younger generation? What's their next step

in this disability rights movement to bring personal assistance and expand it so people can live independently and have choice?

**Judy Heumann:**

We as people who are using personal assistance need to allow people who are younger to understand that they may need a little or a lot of personal assistance as they get older and that they don't need to be looking at going into a nursing home or into a more restricted lifestyle. And I think families need to understand that this is a service that also should be paid. In some cases, the family may be providing the service in which case I believe their families should be paid for the work that they're doing. The Biden administration really is aggressively looking at providing a significant amount of money for home and community-based services that would get rid of waiting lists and allow disabled people who meet the Medicaid eligibility and also would be paying an appropriate wage for people who are doing this work.

Obviously, people need to be paid an appropriate wage so that they're able to live their lives like other people, and I think that also raises the value and respect that people are given. So but right now the Medicaid proposal that the Biden administration has put forward, hopefully because of work from many organizations like yours around the country, enabling elected representatives to understand what it is we're talking about. Because I think there's some sexism that goes on here where there's a presumption that if you have a child, for example, that it's the mother's responsibility to assist the child even though the mother may need to be working and many other things. And it shouldn't be an obligation. Families are supporting their children.

But one of the reasons why I think personal assistance is so important for younger people is it also helps younger people begin to make decisions. So when my mother was my primary provider of personal assistance and she was also taking care of my brothers, two brothers, when I wanted to fish around the closet and figure out what I wanted to wear, she really didn't have the time for that. So if I had someone who was helping me, I could do all the silly things that younger people do. Try on clothes to say, decide they don't want it, take it off.

These are all things that I think really help people learn how to make decisions which as they're getting older will really be helpful for them in their education and in the world of work. And I believe it's really important, as I've been saying, that we need to see this as something which is intergenerational. Elected representatives really need to understand why this is important, and I believe that we're headed in the right direction.

There are more disabled people in the United States and around the world who understand the importance of personal assistance, enabling us individually to be able to live our lives like others. And I think that's critically important, and I really continue to want to emphasize that this is not something that's just beneficial for younger disabled people but is beneficial for people regardless of their age. And we need to really have people intergenerationally have an expectation that they have a right to personal assistance service, and we need to really look at going beyond current Medicaid rules.



Because someone like myself is not eligible under Medicaid because I've been fortunate to be able to have a job where my savings and earnings don't allow me to get that program. But there are other ways that this can be done. So thank you all very much.

**Michael Murray:**

Thank you so much, Judy. We are really honored that you took the time to be with us today.

**Holly Carmichael:**

Yeah, absolutely. Thank you.

**Judy Heumann:**

Talk to you both soon.

**Holly Carmichael:**

Yes. Bye, bye.

**Judy Heumann:**

Thank you. Bye.

**Michael Murray:**

Wow, Holly. That was an incredible interview.

**Holly Carmichael:**

I know, right?

**Michael Murray:**

I just love Judy Heumann. She really rocks my world, and it really helps us, as we're forming this, it's about know, speak, act. We've given you the knowledge to recognize the problem, which is home and community-based services and personal assistance services aren't available to everyone. We've talked to an expert, a general in the disability rights movement, Judy Heumann. And now we're going to close out this episode by giving all of our listeners some ways that they can take action.

The first action that you can take is you can talk about this. So many people end up in nursing homes and congregate settings not because they want to be there but because they didn't know that there were any other options. Even though we know that home and community-based services is so much of a better option, whether you want to be happier or healthier, living in your own home is the best way to do that, and there are great studies out there. We'll put these studies on our website. They're just great studies.

But also, during COVID-19, it's been shown to be a much safer option. So one really interesting study in 2020 in Connecticut, one-third of nursing home residents tested positive for COVID-19. Guess what it was for people receiving home and community-based services? Take a wild guess. Two percent. Two

percent of participants receiving home and based services tested positive for COVID-19 in the same five-month time frame.

And so again, it's healthier, people are happier, and frankly, it's safer.

**Holly Carmichael:**

And you have no choice and control when you're in a congregate setting like that about what time you get up, what you eat, who helps support you in the shower or the bath. I mean you nailed it when you said lack of information is a huge barrier. So make sure that you're thinking about this option if you or a loved one face this. Because we all have a high probability. We're more likely to need long-term services and support someday than not. And we all want choice and control over these things. And so we should be making sure that it's available to everyone. And there's this great progress being made right now, a lot of it because of this COVID-19 stuff.

I think it really highlighted how congregate settings aren't that great for folks, right? They're not having as good of outcomes, they're more costly, and people are literally dying because of this COVID-19 pandemic living in these institutions. And so a bill was recently introduced in the Senate to make sure that home and community-based services could be an entitlement, not just this added waiver program to Medicaid. It should actually be an entitlement.

Why are we putting people in more restrictive settings that cost more, that produce worse outcomes? It doesn't make any sense. And our action today is for you to contact your representative. Make sure your voice is heard. If you're using HCBS or someone you love is using it or if you're in the 70% of folks who might need it someday, we need you to advocate for it. We need you to speak up. We need you to make sure that this entitlement becomes a reality. And we'll make it easy. We'll have some website links I think, right?

**Michael Murray:**

Absolutely, yeah. And we're going to put it on there so that you can go on there and you'll be able to click a few buttons and send an email to your Congressman. So you just go and visit us on [gtindependence.com/episode1](https://gtindependence.com/episode1) and you'll be able to have easy access to these resources.

Because, Holly, we need to make systematic change too. It's not just about what can you as an individual do. We have to make big sweeping changes in the way that we do government.

**Holly Carmichael:**

Yes. Because there's too many people waiting. I mean it's just, we've waited too long. It's time. It's time to get this passed.

**Michael Murray:**

And lastly, we wanted to give you one final action that you can take which is going out and finding a good organization that you can contribute to. So today we're going to be highlighting the organization

called Applied Self-Direction. And Applied Self-Direction is an organization that has a ton of experts that can help with complex operations and infrastructure necessary to create an authentic self-directed, person-centered environment that meets all the federal, state, and local rules and requirements. And this includes experts on labor law and tax law and employment law, Medicaid rules, and everything that comes in so that everyone has access to home and community-based services.

**Conclusion:**

Thank you for listening to the Disability Garrison Podcast. My name is Debbie Todd and my son Blake directs his own services in Michigan through GT Independence. What we like most about directing our own services is that Blake gets to advocate for his own choices, to live in his own home, and have the daily activities and quality of life that he chooses. For the links and resources mentioned in this episode, please go to [gtindependence.com/episode1](http://gtindependence.com/episode1).

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