Participants:
Holly Carmichael
Michael Murray
Judy Mark

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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.

If you acquire a disability, let's say that you were in a car accident or anything else that could happen, you get older and you just need support, you have a few choices. One, you could go live in a nursing home and be able to get the support that you need to take care of your daily life functions. Honestly, nursing homes are not great places. They often lead to abuse and neglect, and even the best ones, your choices and your independence are substantially limited.

The other option, and this is a much better option, is you can have something called home and community-based services paid for through Medicaid. This is an incredible change within our system, and we've started to see more and more people choose home and community-based services.

And we encourage you to go check out some of our previous podcasts on home and community-based services, **specifically the one with Judy Heumann.**

Now, inside of home and community-based services, you've got two different options on how you can have those services delivered. One is you could work with a typical staffing agency, and that staffing agency is going to send somebody out to you who's going to take care of your needs, like taking a shower or bath. But, if you're like me, I personally want to pick who's going to give me a shower or take care of my most intimate needs.

And oftentimes, when you're using a staffing agency, the reality is you don't have that option to decide who comes into your home, when they come into your home, how much they're getting paid. All of these things are left outside of your control, and that's why we at GT Independence support something called self-direction.

Self-direction means that the individual has the opportunity and the right to control their own services and, in some places, even the budget and how much a direct care service worker or support staff gets paid. We believe this is the best way to provide services for people with disabilities, and that those of us with disabilities want control and independence of our own lives.

Holly Carmichael:
Self-direction is rooted and founded in this idea of self-determination, this inalienable right of all people, regardless of your age, your ability to make basic choices about your life and choices we all take for granted, probably.

Did you choose what time you would wake up, what you'd wear today, who you'd spend your time with, where you’d go, what you'd eat? These are all choices that can be taken away when you acquire a disability. And self-determination has these five key principles that are critical, including freedom. The freedom to determine what a meaningful life means to you, the freedom to fail, the authority, authority to choose who helps you with your most intimate care needs, the authority to train someone in how you prefer to receive your care, the support to do that, to get the resources to meet your needs, responsibility.

Of course, we all have to be good stewards and wise use of public funds, but mostly, confirmation that you're in charge of your own life just like we all would want. And in this concept of self-direction, it's not new, but it's not available everywhere despite research showing that it produces better outcomes for people. People are more satisfied with their life. And isn't that what we're trying to do in the service industry? People want a good life, not a good service. And they want to be in charge of their life. Self-direction reduces somebody's unmet care needs, and it makes primary caregivers significantly more satisfied. There's that reassurance that the person is in charge. Participants and their own family members are really truly the experts, and we need a paradigm shift here.

Right now, there is only self-direction available on about half of our HCBS waivers. And even then, it's not utilized heavily. And when you talk to someone, to your friend, to a stranger on the street and walk them through what choice they might make when faced with a disability and help with their intimate care needs, everyone chooses self-direction. You want to have that choice. I and all of us at GT Independence firmly believe in this. We believe this is a right for everybody that they should be entitled to. It shouldn't matter where you live or which waiver you qualify for. You should have a right to make choices about your life.

And we are so thrilled to talk with our next guest and honored to serve her own son. She works in the state of California to make self-determination a reality and has been fighting for tens of years to make that happen. And this past July, we finally were able to open it up statewide, but there are still barriers that exist that you'll hear her talk about. Please without further ado, let's get into our conversation with Judy Mark.

We are honored to interview as our guest Judy Mark who is the President and founder of DVU, which is Disability Voices United here in California. And we're going to chat with her a little bit today about a topic very near and dear to our hearts and that really inspired and spawned the creation of our company GT Independence, this concept of self-determination. So welcome, Judy. Thank you for joining us.

Judy Mark:
Thank you for having me.

Holly Carmichael:
Awesome. I'm really curious to get your take on what you feel self-determination means to you and your family.

Judy Mark:
Self-determination for me is a civil rights movement. It's not just a program or an option that people can have to direct their own services. It really is about true civil rights for people with disabilities. What most of the traditional systems in the country look like is that people with disabilities are told what they do every day, who they spend their time with, where they go, how they live, where they live. And this is not appropriate. This is not the same kind of civil rights that people have who don't have disabilities.

I have a son who's 25 now with autism who is self-determined. But for most of his life, he wasn't. He's only been in the self-determination program for a couple of years. So what we saw as the life of a person with a disability and their family is that we're told, yes, you have this diagnosis and here are the few services you're eligible for and here are the few agencies that are willing to provide you with those services. And if you don't like any of them, then you're out of luck. And I still know many, many people who are stuck in that in that old way of thinking.

And so when I first heard about the self-determination program, it was actually from people associated with Michigan and with GT Independence, with the self-determination program in Michigan. And I heard about how it worked there and what people are allowed to do in their lives. And I'm like, sign me up for that. How do I get in that? And so for me, I have seen the difference in my son's life. I see it as just basic human rights that people have choice and control over their lives.

Holly Carmichael:
Yeah. No. You really hit the nail on the head. I mean a frustration of mine is sometimes we'll go to these conferences within our field, and people describe this self-directed or self-determination program. But it's this way of life, it's this philosophical belief that all people regardless of their abilities or age have the freedom to make choices about how they live their life, what they do with their life, who they spend their time with, where they live, and just like you or I would want. And it's unbelievable that we're still in 2022 having to make the case that everybody should have choice and control over their life.

Michael Murray:
Absolutely, yeah. Judy, I'm curious for some of our listeners who may not have heard of self-direction, if you could talk about some of the changes that you saw in your son going from a non-self-directed experience to being able to control his own life and have his civil rights. What did you see?

Judy Mark:
Well, I can tell you that when he left high school, he didn't finish high school, and we were able to get him out at 18. And he was offered by what we have in California, what they call the regional centers. Regional centers are the non-profit agencies that are completely government-funded to tell you what services and supports you're allowed to have.

And they said to him, okay, you are going to go to a day program because there's no way you'll ever work. So let's put you in a day program, and here are three of them. Go visit them. And so I didn't know what else to do. So my son and I went to visit them. He walked into one of them. It was a self-contained like big warehouse, and he literally walked in the front door and said—my son doesn't speak very much, but he can certainly make his wants known.

And he said, “I'm out.” And he's like, “bye.” And he walked out the door.

I don't know that he actually said the words "I’m out," but he left. He like did not want to be in this giant, echoing warehouse with all these people. The second one we went to I thought would be much better. It was all based in the arts, and you spent the morning doing theatre, and then you do singing, and then you do dance. And you go to different rooms, and you have lunch in between. And it seemed really fun. And he lasted about one hour, and he wanted to be out in the community. He wanted to go out for lunch. He wanted to be walking down the street. And all he did was stay in this building.

And so I sat and talked to the director. I'm like, "Are you open to people having a more individualized way of accessing your services?”

“Nope, this is the way we do it. And the ratio is 10-to1 and if he needs a one-to-one aide, he cannot be in our program.”

Which my son did need a one-to-one.

And finally, we settled in on a program that allowed him to basically not be part of the program, that we would just funnel the money through them. He had a one-to-one aide who would come to our house in the morning, and he kind of did what he wanted to do and kind of lived a loosely self-directed life within the confines of this day program. However, the salary paid to his staff was quite low. Cost of living in California is extremely high, and they were making a just a dollar above minimum wage, about $15 an hour. That is not a livable wage in California, and they wouldn't put him above 30 hours a week so that the staff couldn't get health insurance.

Michael Murray:
Wow.

Judy Mark:
And it's really hard to keep staff when that's what you're asking for. And yet the agency is pocketing way more than $15 an hour because they have a copy machine and they have a phone and they have staff and they have managers of staff and they have all these different levels, none of which my son was accessing or benefiting from.

So when he entered the self-determination program, we were able to keep the staff that he had through this through this agency. We were able to give them a double their salary. Like literally double their salary and provided healthcare and did not spend any more than we were spending in the traditional system.

Michael Murray:
Wow.

Judy Mark:
Because my son was also getting other services that he hated, but they were still being offered to him. Like this person to come in and help him learn how to wash his clothes and cook. He didn't want to learn from that person, but we were still paying to have that person come in. Instead, we could use that money towards the aide that he knew and trusted, and then we actually spent additional money to train that aide in how to provide that kind of life skills work. So his life has really changed.

And then of course, COVID hit, and we were able to manage COVID in a way through the self-determination program. He would have never managed it because just like throughout the rest of the country, all the congregate day programs shut down, and they couldn't have people in these giant groups anymore. And so we ended up being able to take some of the monies of some of the classes he was going to take—it all shut down—and put it towards increased staffing, increased availabilities to do other kinds of things. And it's really helped us weather this very, very difficult last couple of years.

Holly Carmichael:
Yeah. Well, you hit on a number of benefits that self-direction brings, like being able to pay a living wage to staff and being able to choose who you want to have for as many of the hours of your time that you need and be able to perhaps even add benefits or pieces and just control what you do. My brother-in-law Ben has a very similar story, was kicked out of multiple group programs because he didn't want to go bowling.

Judy Mark:
Yes. My son hates bowling. He hates anything where there’s an echo-y sound which definitely there is in bowling.

Michael Murray:
Well, and I just feel like I would get kicked out of those programs too. I've never been really good at doing big group activities.

Holly Carmichael:
Definitely get kicked out.

Judy Mark:
It's funny because I think about my mom, my mom who would be 102 now, literally 102. So she's no longer alive. But she had Alzheimer’s at the end of her life, and she always said to me before when she was younger, “Don't ever put me in a home with a bunch of seniors where they all just sit together and do everything together. That's not what I want in my life.”

And sadly, that's where she ended up at some point when she was first diagnosed. And even though she couldn't really express it, she was miserable. That's like what my son is feeling. And we actually got her out, put her into an individualized place, and she ended up spending the rest of her life in a much more peaceful way.

And that's really what self-determination is. It doesn't matter whether you're an older person with Alzheimer’s or a young person with autism or a person with mental health disabilities or a veteran or whatever it is. People should be able to have choice and control over their lives. And so before starting this little podcast, we got some water delivered to us, and the water is called Paradigm, which I thought was really quite appropriate because this really is a paradigm shift that is not easy for everyone to take.

So I'll start from the beginning of when I talk about a paradigm shift. So it's certainly not easy for the professionals who have been saying to us all along, “This is what you shouldn’t do. We know better than you because we have PhDs in autism or in psychology or whatever. And we know better than you. So do what we tell you to do, and everything will be okay.”

It's a paradigm shift also for parents like me who are having to step back and say, “Wow, a person-centered system is not always the same as what I want, and that makes me very uncomfortable.”

I always tell parents that if you're at a person-centered planning meeting for your child and you're not at least at some point uncomfortable, then it is not a true person-centered plan. And then finally, it actually makes self-advocates uncomfortable, and it's a paradigm shift for them because they are so used to being passive and being told what to do that when they're finally given a choice, they're like, “I don't know. I'm kind of happy with the way things are right now.”

Because they don't know anything, right? It's very scary. There's a huge fear factor completely here in California and maybe in other states. But here, there's a lot of self-advocates and family members who are scared to question authority, to question the status quo, particularly people of color who suffer from tremendous racial and ethnic disparities.

And many people are seeing the self-determination program as a way to bring back power to us, the power to the people who created the Lanterman Act, who created the Developmental Disabilities Act, and the federal government, to fight for our rights every year. And it's really hard. This paradigm shift is really hard for everyone, from the government who was so used to saying things like, we're going to bring together all the stakeholders here, and they consider the regional centers as stakeholders, the service providers as stakeholders, and the families and self-advocates as stakeholders. And I always have to remind them, wait a second, the self-advocates are the stakeholders here. They're the stakeholders. The families are part of that, particularly with younger children, are part of those stakeholders. And everybody else gets paid to be here.

Holly Carmichael:
Yeah, that's right. That is absolute right.

Judy Mark:
So like don't tell me you're bringing together the stakeholders. We're the stakeholders, and everybody else can chime in when you're asked. And so that sort of massive paradigm shift makes it very difficult for the self-determination program to really move forward and become successful. And it makes me not the most popular person on the planet or certainly not the most popular person in California. I have lots of hate mail.

But I really feeling this—I spent my entire career in the civil rights movement I have fought for women's rights. I have fought for students’ rights. I have fought for immigrant rights. Most of my career on immigration and refugee rights. And this to me was just a natural extension of all the work I've done in my life by saying, yeah, hey, wait a second, my son is just the same as immigrants, people of color, women. It's the exact same civil rights movement. So yeah.

Michael Murray:
Well, and I think for those of us with disabilities as well, it is a paradigm shift when you grow up in a system that is constantly testing what you're bad at. And I experienced this as a person with a disability growing up with my disability. You are constantly being reinforced about what you can't do.

And then all of a sudden, Judy Mark comes along and says, you can do it all and you can direct and control all of your own services. And you go, oh my goodness, what? It is. It's a paradigm shift, and there's a certain amount of deer in the headlights kind of feeling.

So I think for all of our listeners, as you're thinking about this and you think about what Judy just said, if you're not uncomfortable with this conversation and with the way that you're moving forward, then press on. Get uncomfortable. Let's get uncomfortable and push self-direction forward because that's what we're going to see. That's when we're going to start to see the rights of those of us with disabilities fully enforced. And that is worth fighting for, and that is worth getting uncomfortable for.

Holly Carmichael:
It is. It absolutely is. I love your statement though. I'm definitely going to use that. Who here's getting paid? If you're getting paid to be here, please step back a little bit. If you're not getting paid, please step forward. That's a great point.

And I think the comfortability of the box, like oh, here, I have program option A, B, or C, and I'll figure out which box best fits you. It's easy and like you said, that's how the system's structured. And there are people who are financially incentivized to keep that system that way and to say, “No, no, no, a person with a disability doesn't have this capacity to make choices or run their own life.”

And like you said, even when they're given the option, there's a lot of fear. And when you haven't had those choices—I'll never forget working with the gentleman. I'll call him Al for this sake. But I was working with him on helping him find employment, and we were just going through really a basic kind of get to know you and understand. And Al had done real work in the past. He had acquired a disability from an injury, but he was very young. And now it's been decades since then and had lived in a group home.

And so we were talking about well, are you more of a morning person or like an evening person? Like can we do an early first shift or early job? And he said, “I'm not sure. Let me ask Sally.”

Because even a decision about am I a morning person is—I mean one of my first job in college was working in a group home. You get up on the schedule, you take your meds on the schedule, you eat what's on the table, and you talked about the HCBS settings role. I think it beautifully ties in with self-direction and self-determination and is a great way for states to embrace self-determination to help implement this settings role too.

Because I think it was an amazing thing that the Obama administration did to recognize like, hey, we have these providers who say they're providing home and community-based services, but then when you go visit them, really, it's just a smaller version of institutional based care. It’s a congregate setting. Like you said, there's a schedule. There's a schedule of activities, and there's ten-to-one and you have to fit the box or you get care.

Michael Murray:
Well, and I'll never forget, I worked at a P&A, and we had the responsibility of going around looking at these institutions. And somebody was brought a new shirt from their parent, and they were given the shirt and wanted to put it on. But their worker was like, “No, no, today's Tuesday. Tuesdays, we wear this.”

And the person went along with it because that was what they had been taught to do. And for our listeners who can't see Judy's face, it was priceless. We should capture that because that's the appropriate face. Are you kidding me? You're picking what people are wearing? Is that really? Just so much.

So Judy, you are an incredible community organizer. We work with a lot of people in a lot of states, and I have also worked with a lot of people throughout the country. And watching you engage on the ground, get people rallied around a program, getting them going is a force to be reckoned with. And a lot of our listeners want to do the same thing. They want to do the same thing in their state. There are things that you can fix, but man, we are headed in the right direction in California and that is in large part because of you and the advocacy of the people that you work with.

If you could give some advice to some of those other folks who want to organize on the ground, who want to think about, "How can I get a group of people together to fight for self-determination?" What are some of the things that you'd have them think about?

Judy Mark:
Wow. That's a great question. I've been a community organizer my entire career, and nobody's ever asked me why it's important and how you do it. So I appreciate that.

It's funny because it's come up recently that the term inclusion is important, but not the kind of inclusion in the disability context. It's that no group in your coalition or in your community should be considered better than the other and that the way that you get things accomplished is by being inclusive as opposed to being exclusive. And so the way that a lot of laws have gotten passed in California, including somewhat of the self-determination program, self-determination law was by a small group of people who knew how to work the system, who knew how to get laws passed, who knew the right people in Sacramento which is our state capital. And that's how they got things done.

And I started realizing that's not fair because that's not including the Spanish speakers and the Korean speakers and the other communities that we work in, and it's not including self-advocates most of the time. And so we're always trying to bring people in. In fact, tomorrow I'm having—

It's actually so much easier, by the way, to do it during COVID because you can get anybody to show up to a Zoom meeting. It doesn't matter where they are. California's a too-big state, and you can drive 15 hours and still be in the state. So it's a very large state. And so instead of me traveling up and down the state and talking to people in person, as much as I love that, I pulled together, we're having a meeting tomorrow where we're talking about this.

And to me, it's like let's bring in people, let's include them. And when I say people, I mean people with disabilities and family members. I don't always keep the same place at the table for people who are paid to be in our system. Doesn't mean that I don't always want to work with folks who are like-minded like

GT, like we have an incredible coalition of supported living providers. And I work with any kind of group including our P&A, our disability rights California all the time to get things accomplished.

But the voices that I want to hear the most are people with disabilities and secondarily, their families. And by the way, that's really hard. Like I just want to spend a minute talking about how to always have a face and the voice of the person with a disability out front. I've worked in public policy and in non-profit organizational stuff my entire career, and I'm not that young anymore. I'm going to be 60 this year. And so that's a lot of years of experience. I know that I have more experience than a lot of people. And I can do public speaking. I know how to make my points very succinctly. I can do a sound bite in the media any day of the week.

But that doesn't mean I should always be the one doing that. And so I have really been trying to mentor and to train people with disabilities to take my job, to take my place because I would love to sit on an island in Hawaii and watch people with disabilities take over the whole disability rights movement in California. I would be thrilled to do that.

My son is not one of those people who could do all this. Doesn't mean that he doesn't want it to be done, but he's not going to be able to do that. But there's a whole lot of people who can, and we have on our staff at DVU some incredible people with disabilities who I am grooming to take much bigger leadership roles and understand how to stand up at public meetings and make persuasive cases. They're the future. They're the future of the disability rights movement. It's not me. It's not even my daughter who's a sibling, who I know will be a great advocate for her brother and will probably go into this field in some way. But it is the people with disabilities who have to get out there.

Holly Carmichael:
That representation and speaking up is so important, and we'll recap this as one of our actions. But public comment, a lot of these programs, certainly Medicaid HCBS programs have to go through a public comment period. And that's an opportunity for anybody, an ally, people with disabilities to make sure you speak up if self-determination isn't offered because it's only on about half of the HCBS waivers in this country, only about half.

And for whatever reason, I mean I think we can dive into a little bit, we've touched on some of the barriers that exist at that paradigm shift and this almost stigma that exists around whether or not a person with a disability has the capacity. And it's unfortunate.

Another one that we sometimes face is this perception of fraud even though studies have shown and even within our own government, I mean I call out the OIG a little bit here. They put out a report that said self-directed programs are, the words they used were ‘particularly vulnerable.’ Had no data to support that statement. That was just the author's feelings. And a great national group of applied self-direction asked him to show the data to back it up. They didn't have it.

Judy Mark:
Yes, because it's ableism.

Michael Murray:
Yes, it's ableism.

Judy Mark:
So you have the ableism that people can't make their own decisions, that person-centered planning is a joke, that if you just put them in a room and give them some busy work to do, they'll be happy, and that if you give them some sort of freedom, they're going to take advantage of it.

One of the big things that happened in California is that people wanted to purchase Disneyland tickets with their self-determination funds which was, “Oh my God, that is like just ripping off our state taxpayers to go to spend $150 to go to Disneyland.”

But for some individuals, they literally never go anywhere, they never do anything, they never go walking, and yet they might walk 10 miles while they were at Disneyland. Yet that was taken off. You cannot have Disneyland tickets because that looks very fraudulent. But I believe in self-determination, people are actually more responsible, more responsible for the funds that they have.

One of the founders of our self-determination program is a man named Harvey Lapin who is from Detroit, Michigan, very a big Michigander. He talks about for every single rule that is created in the self-determination program, every single problem, every single challenge, you should ask who's in charge. And if who's in charge is the paid people, the professionals, the regional centers, the government, then it's not self-determination.

In almost every case, the person's not in charge. And so it's like the program is not meeting its potential because the law is not being followed in the way it should be.

So we have a long way to go. The good thing is that the people who have gotten in finally figured out how to get into the program, so incredibly happy with where they are in their lives and what they're doing that they're like the biggest fan boys for the program. And they're just going, and the parents in particular will go anywhere, will speak anywhere, and say, tell me who I need to talk to say how great this program is. And if they ever tried to scale back the program or scale back in any way, there would be protests in the streets of Sacramento because people love this program so much. I just want to tell a little anecdote.

So last year, just about a year ago, there was a budget hearing in Sacramento. Now, of course, because of COVID, it was on Zoom. And the state senator whose budget committee, she was chairing this budget committee, knows zero, nothing about the self-determination program. She knows absolutely nothing.

But there was an agenda item where the head of our department of developmental services said, “Yeah, there's only 400 people in the program at the time. It's going statewide. We were hoping there would be 2,500 people.”

And so the senator said, “Well, it's kind of like a restaurant that has nobody eating there. I mean, maybe it should close.”

Michael Murray:
Wow.

Judy Mark:
And you can imagine, I blew a gasket on that. And the great thing is that I didn't have to do it from sitting inside a hearing room. Everything was on Zoom or whatever the system was.

And we were able to get out on social media and get out an email saying, “Here's a phone number, call it and defend the self-determination program. Here is what the senator said.”

So you had like one person after the other calling in and saying, “I love self-determination. It's not like the restaurant who has no customers. It's this is a restaurant where we are lined up around the corner to get into, but there are these giant barriers in front of the door that are not letting us in. And we know that inside there's this incredible menu of things that we can do, but we're not able to get access to it.”

And there must have been like 30 people who called in to provide public comment to make that same statement about the restaurant. And by the end, she was like, “Okay, okay, I get it, I get it.”

And this year now, it's a year later, and she just had her hearing last week and they did not have a panel about the self-determination program this year. It was literally the first thing she said was, “Just want to let everybody know we're not talking about it today. We plan to have a special hearing about it next month we promise.” Like don't bother me.

And that is what you were saying before, Holly. It's the power of public comment. That's part of power. And by the way, power is an illusion, everybody, because you get 30 people to call in. I mean that's not a lot of people for the state of California, right? We have 430,000 people in the system. 30 people is power because they've taken time out of the day to pick up the phone. They had to wait on hold for a couple of hours, and they gave their comments in all different languages. And she heard us.

And so that's what we're trying to create here with self-determination being the center. But we're trying to create a disability rights movement in the state that really talks about people's choice and control and meaningful outcomes that matter to us.

Michael Murray:
That is a powerful vision for the future, and we plan on being with you every step of the way. And we're going to fight for that because that just gets us excited at GT. That is our big, hairy, audacious goal that everyone has the option to self-direct.

If you're a listener right now, you may be hearing some of these problems that were we're fighting against and thinking, “Man, maybe I'll wait till they figure it out before I join the self-determination program.”

But I want to go back to the start of this conversation and say if you're not slightly uncomfortable, you're not moving in the right direction. Self-determination is worth it. All of the benefits that we outlined at the beginning will revolutionize your experience as a person with a disability. We know it, and we've got thousands and thousands and thousands of people with disabilities who can testify to this. And if you want to hear some more, man, we can give you some more. Give us a call. We'll let you know. And then on top of that, you've got some really great folks who are going to come alongside you and support you.
I know at GT Independence, we are really good at removing barriers or at least helping people figure out ways to get around those barriers. And so join the fight. Join the Disability Garrison. Join us in this revolution.

Sitting at the Woolworth counter was not easy, but man, you could say you were there. Isn't that what we all want? To say that we had an impact in our lives? And so I would encourage all of our listeners, if you're thinking about the self-determination program, we can help you. We're not saying it's going to be easy or fast, but we can help you get to it.

And when you do get inside, I think it's like Judy said, man, the menu is incredible. It is the best menu that you could have, and it is totally worth pushing forward to get. So I'm going to turn it to Holly for final thoughts and then Judy to close us out.

Holly Carmichael:
Yeah, Michael. I would just echo your comments. We believe strongly and are very passionate about self-determination. Of course, we've lived it and gone through similar to Judy's son. My brother-in-law Ben has a very similar story and now my daughter Maggie. I can't imagine not having that choice and control over who provides her care.

And when we think about our own selves and when you put yourself into the position of imagining maybe the last time you performed an intimate care need, like the last time you went to the bathroom and imagine if you needed support or help doing that, not being able to choose who did that for you, not being able to fire that person if you didn't like them or if they weren't doing a great job. I mean these seem like such simple things, choices we all take for granted, and everybody deserves to make choices.

And I would just say regardless of what state you live in, self-determination should be available to you. You can reach out to us even if we don't serve that state. We'll help point you in the right direction and make sure you know about the options that you have and that you know about programs that you can comment on and add public comment.

Like I said, there's about half of our HCBS waivers where there's a gap, and self-determination is missing. And I just talked to Senator Peters this weekend, and he didn't know what self-determination was. Gosh darn it.

Michael Murray:
He does now, I'm sure. Holly got hold of him.

Holly Carmichael:
Continue to educate. So Judy, closing thoughts. Thank you again.

Michael Murray:
Thank you, Judy.

Judy Mark:
Thank you. Thank you, GT, for bringing self-determination around the country. I think that we have a long way to go with the ableism that exists in our society where people think that people with disabilities are lesser than. It's no different than any of the civil rights moves we've been in. And so this is a long road.

We're not going to succeed anytime soon, but we believe that self-determination is just one piece, that there's other pieces including making sure we're voting and making sure that conservatorship reform exists, and that we have supported decision making, and that people live in the community and have access to employment. Self-determination is just one of the many pieces that that has to exist. But for us, it's really the center of what we do because if you can't really control your own life, then why exist in the world? I mean why exist? And so we're hoping that young people are going into the self-determination program, and it's going to naturally change the paradigm, just like inclusion is much more common now in classrooms than it was certainly when my son was in school and he's only 25.

And so I agree with what's been said. And try self-determination if it's something in your state that exists. It is absolutely worth it, not only because you get all these choices and you get to do all these cool things and you get to join a gym and you get to go have fun and you get to live your life in the time frame that you want to live it as opposed to “Sorry, shift change at eight. So sorry, you can't go to dinner, and you have to be home from dinner at 8 pm.” It's also because we need to believe in people with disabilities.

I mean we need to believe that people with disabilities have the same rights that people without disabilities do, the same rights to live their lives, to make their own choices even if they are highly impacted by their disability, even if they are not able to communicate in spoken word what their preferences are, that in whatever way people can communicate what they want in their life, they should be able to have those choices and eat and also have the dignity of risk to make those mistakes and then learn from those mistakes.

So most days I'm quite optimistic about the future. There are some days that really bring me down, beaten down by the system. But most days, here's what I can say is that here in California, people are saying the right things. Before, they weren't even saying the right things. Total lip service, but at least they're saying the right things. And now we have to get the actions behind those words. And so we're moving forward. I feel hope for the future, and I'm excited to join arms with you to make it happen.

Michael Murray:
That was absolutely an incredible conversation, wasn't it, Holly?

Holly Carmichael:
What a tremendous advocate. I feel so lucky that we had the chance to sit down with Judy for this episode.

Michael Murray:
And she really tells us that if you're willing to push for it, if you're willing to fight for it, you can have self-direction in your state, in your waiver, and have access to it. And I just think that she's a shining example of what it means to make true change, and that's how we want to end this podcast.

As you know, we always end out the Disability Garrison podcast by giving you three ways that you can make a difference on this particular topic. We give you something that you individually can do, we talk about a systematic change that you can make, and then we talk about an organization who's doing great work that you can contribute to.

So the first thing that we want to encourage you to do is be educated about home and community-based services and the fact that self-direction is an option. So many folks believe that if they acquire disability or if they have someone who's aging that needs additional supports, that they have one option, and that's to go into a nursing home. And that is not true. We've got to fight that perception, and we need to ensure that everyone knows that they should have the right to remain in their homes. We want everyone to have the right to remain in their homes, and we should fight for that.

And additionally, being able to self-direct your own services while in your home is the best way to do it. So we really encourage all of the folks, you go online to gtindependence.com, check out more of our resources around self-determination. We really believe that it's a powerful tool, and we want everyone to be educated. And that's what you individually can do.

Holly Carmichael:
Yes. Once you educate yourself, we want you to advocate. There are still over half of our HCBS waivers missing self-determination as an option, and that's not okay. And your voice matters.

There is a beautiful process that that allows for public comment on all of these things that use your public dollars to pay for. So speak up, comment, and advocate on those. Ask for self-determination and choice and control over your life, letting your loved one have control over their life. It is so critical.

Again, as Michael mentioned, go on to the website, check out, we will give you resources there that help you navigate and figure out what waivers are in your state, where you can comment, and how to make that happen. But we need people to care and to comment and to advocate for self-determination in your state.

Michael Murray:
And lastly, we want to give you an organization that you can donate to, and today our job’s really easy. We want you to go and donate to Disability Voices United. It's an organization that we are proud to support, and our guest speaker today Judy Mark has helped start that organization and has worked with an incredible group of advocates in the California area to ensure that self-determination is available to everyone in California. And they have done it. Holly, they did it.

And I believe that we can follow their example, and we can ensure that in every state, everyone has the option to self-direct. To all of us here to all of you out there in the Disability Garrison, thank you for continuing to fight for justice and equality. We're proud to serve alongside you.

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