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**Hosts:**

Holly Carmichael  
Michael Murray

**Guest:**

Melissa Schlemmer

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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:**

I want you to imagine for a moment that you're the most qualified person to provide care and do a job, but you're not allowed to, or at least not allowed to be paid for that job. There are hundreds of thousands of family caregivers working unpaid even though they may be the most qualified person to provide the care to their loved one. And when we look at what it actually takes to be a family caregiver, to serve the needs of the person, the loved one, the family member who may have a disability, whether that's 5, 10, 15, 20 hours a day, sometimes round-the-clock care that's needed, is that what we should expect? Is that as a society what we expect of family members to say, "nope, sorry, you've got to take care of that on your own?" And it's really quite silly when we look at it.

As a society, we've agreed. We've all agreed that individuals with disabilities are entitled to receive care, to live in their homes and communities, and we should be paying the best people to do that job. In many, many instances, this is a family member. Yet despite this, only a handful of states allow for family members to be paid, especially paid parents of minor children, and we're going to explore this topic a little bit more today in the stigma that exists around paying family members for their care. We're going to talk to Melissa who provides care to her son who has a rare disease and has significant round-the-clock care needs and her ability to get paid through a program in Minnesota, through Consumer Direction, and what that means to her and what a day in the life looks like for her and Christopher.

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And we're going to explore more why this stigma exists and what we can do to end it. Because we know as a society, we have a caregiver shortage that we're facing, and we know through evidence-based research that family caregivers and self-directed care provides better outcomes for lower costs. We need this. As a society, we need to face this stigma and answer these questions and make sure that we're taking care of every individual in our society in the best way possible. So join us today as we jump in and talk with our guest Melissa about her experience in Minnesota.

**Michael Murray:**

I am so excited about our guest today, Holly. It is going to be a really awesome interview and a topic that we are so personally passionate about. Tell us about Melissa.

**Holly Carmichael:**

Absolutely. Melissa is a dear friend of mine and someone from the PMM2-CDG community, which is Maggie's rare disease. But she is an amazing mother who devotes a lot of her time caring for Christopher. And beyond that though, she's a great writer. You can catch some of her pieces on The Mighty or Firefly, Today's Parents or even Huffington Post. She has a blog called TheSpecialMom.com and her Instagram, @OurRealRareLife walks through kind of the trials and tribulations and adventures that you get into when you're raising a child with a rare disease. And I'm so excited to talk with her today about caregiving and being paid to take care of your child for their personal care services.

**Michael Murray:**

Melissa, welcome.

**Melissa Schlemmer:**

Thank you.

**Holly Carmichael:**

So tell us a little bit about Christopher who started your real rare life. Tell us what is he like and what's his personality like and what do you love about him.

**Melissa Schlemmer:**

Well, Christopher is eight years old, and he is manipulative and silly and fun and so smart. He really is very smart. He is. He knows how to get his way, and he knows just what to do to get his way. Even though he is non-verbal and he cannot walk or he cannot do a lot of things for himself, he definitely knows how to manipulate a situation to get what he wants.

**Michael Murray:**

I love people who know how to advocate for their needs.

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**Melissa Schlemmer:**

Yes. It is funny. One of his teachers had said in the morning when she bent down to say, "Good morning, Christopher," he would shove his hand into her face. And she said, "Self-efficacy. That's great, Christopher." Meanwhile, I told him it was a little bit rude. But he was advocating for what he wanted.

**Michael Murray:**

Well, yeah, don't get in my face. Christopher sounds awesome, and I'd love to meet him one day. Can you tell us a little bit about his needs and maybe even just walk us through a typical day in his life?

**Melissa Schlemmer:**

Okay. So Chris is pretty much dependent upon us, his parents, for all of his daily needs. From the start, from the moment he wakes up, I have to go to his room, I have to change him, lift him out of bed, carry him down the stairs. And then usually that kind of starts our routine of I draw up all of his medication, I give him his medication. And the medication can take anywhere from 30 minutes to an hour. And after that, we are usually starting our activities of playing or he gets a little bit of down time to watch a cartoon.

But everything that he does requires intervention from me or my husband. He doesn't typically do anything without facilitation from us. He can't get to his chair and say, "I want to read books." If he does use his AAC device, I have to present it to him and then model it and coach him on how to use it.

So our days are full of activity. We play outside, we go on walks, we play downstairs. He loves puzzles and books and hand over hand activities. But there isn't anything that he can do without the help of somebody else. I mean obviously it's so hard to say a typical day because his days are crazy.

**Holly Carmichael:**

Yeah, they change. Yeah.

**Melissa Schlemmer:**

I mean I could tell you for 10 minutes I guess what a day is like. This morning he was throwing up in bed, and I had to run to his room and flip him over and take his TLSO off. And he started the morning kind of crazy.

**Michael Murray:**

What is the most charming and the most obnoxious thing that Christopher does? As a dad of a little boy and a little girl, I feel like that's a fair question because every kid has got the thing where you're just like, "Oh, I love that," and then every kid's got the thing where you're like, "I hope they grow out of that."

**Melissa Schlemmer:**

Okay. I think it's the same thing that I would think is charming and my husband would think was obnoxious. Because Christopher will be fine with me. For example, he'll be in his stander, and he'll be watching a cartoon on TV. He'll be happy with the cartoon. As soon as my husband gets home, he will look at him and

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shake his head no and want my husband to change the channel for him because he knows dad will sit there with the remote and change the channel over and over and over again and mom won't do that.

**Michael Murray:**

I love that. My son does the exact same thing. He always wants, we're like, no, this is what we're watching, bud. And no, he wants to change it. So good.

**Holly Carmichael:**

So you, Melissa, you participate in a really cool program in the state of Minnesota called CDCS, Consumer Directed Care Services. And part of that program includes being able to choose who provides personal care assistance and supports Christopher through the day. How did you go about selecting who was best, including choosing yourself in some cases?

**Melissa Schlemmer:**

I think for me it's probably part of my controlling nature. But I knew Christopher best from the start. We were very bonded. I was close to him. I think for me it was kind of a no-brainer that I would be the full-time caregiver for him.

Oddly enough, I was a caregiver for 10 years for another family before I had my own children. So it was so strange to be part of that world as a caregiver and then decide, "Oh, I'm done caregiving" and then have my own child in need of a caregiver. It was just this odd full circle.

But I knew that I knew Christopher the best. I knew I wanted to be part of all of his therapy appointments, his specialist appointments. I wanted to know what was going on in his life, and I wanted to be the one to facilitate everything that needed to happen for him. So I think we just decided kind of without deciding. It was this is what we're going to do.

**Holly Carmichael:**

Yeah. It's what made the most sense.

**Michael Murray:**

Yeah, definitely. And I love the point that you made that you knew Christopher best. And that's what I believe self-determination is all about, is what is best for you and being able to have the opportunity to choose the life that you want and to make choices within that life.

And you have other kids too. Would you say that Christopher's needs and what you need to provide—I know the answer to this—but what you need to provide typical or is it above and beyond what you would typically be required to provide as a parent?

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**Melissa Schlemmer:**

I definitely without a doubt think it is above and beyond what I would provide for a typical child. I have a nephew almost the same age as Christopher, and it is light years compared to what my sister needs to provide for my nephew compared to what I need to provide for Christopher.

**Holly Carmichael:**

Yeah, absolutely. These are above and beyond kind of the call of duty of a standard parenting gig if you will. What do you think, Melissa, what do you think your family or your structure would look like if the state of Minnesota didn't have this cool program that lets you be Christopher's full-time caregiver? What would that do to your family structure and kind of existing life as it is? And how do you think it would impact Christopher's level of care and even all of the amazing things he's grown to do like uses AAC and self-advocate?

**Melissa Schlemmer:**

To be honest, I don't think that Christopher would be as cognitively as far along as he is right now with somebody else being a caregiver. I can know what he wants without him relaying that message to me. I know when he needs me without him using any words because he doesn't use any words. But I can anticipate his needs, and I think to be honest, I don't know that he would be as, I hate to say it, but as well taken care of. I don't think that he would be as engaging. I don't think that he would be doing what he's doing right now if he had somebody else caring for him.

**Michael Murray:**

Yeah. And I think all of these questions are really getting to the understanding that this is above and beyond what you would typically be required to do, that it is something that is of value to your son, to your family, and that your ability to be reimbursed for that is vitally important to your family structure but also just to those around you and to the community that you're in. Can you tell us a little bit of what you would say to a state or policy maker who doesn't believe that parents of minors or spouses should be paid for the personal care that they provide?

**Melissa Schlemmer:**

I would say that the best provider of care would be a family member that knows the person the best. I feel like given an opportunity to be that person only helps that person thrive in the community that they're in, in the environment that they're in.

**Holly Carmichael:**

Yes. And for those people who believe that oh gosh, family members could take advantage of this and just get paid for not giving the actual care, what would you say to that? Do you think that that could actually happen in a model of a family member?

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**Melissa Schlemmer:**

I really don't think so. It's only helping a person thrive. I don't think that anybody is going to not provide care for that person. It's the only way to make sure that person is well cared for and safe and not being taken advantage of. I don't think it's the person providing care that would be taking advantage of anything.

**Holly Carmichael:**

Yeah. And you still have, like Christopher has a case manager who's checking in regularly and assessing those needs and checking in with you on how things are going. It's not like these family members are just written a check and say, "see you later."

**Melissa Schlemmer:**

No, definitely not. I have active county case managers and a county nurse and people that check in regularly with us. And they know where to find us, and they'll make sure that Christopher is well taken care of. They come into our home a couple times a year. They look at him. They can see that his needs are above and beyond a child his age. They know that I'm definitely not taking advantage of anything.

**Holly Carmichael:**

Yeah. What would you say is—I'm curious. I know I have learned a lot of things from having a child with a rare disease. I know you write a lot about this on The Mighty of different lessons you've learned or taken away. What's something that you feel like you've learned from your experience of being this amazing mom to Christopher?

**Melissa Schlemmer:**

I think Christopher has given us a greater perspective than we ever could have learned anywhere else. He really has opened our eyes to see that your life might not be what you planned it to be, but it can still be this amazing, beautiful life.

**Holly Carmichael:**

Yeah.

**Michael Murray:**

I love that.

**Holly Carmichael:**

He's a pretty great kid.

**Michael Murray:**

Melissa, thank you so much. We were really honored to have you on today.

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**Holly Carmichael:**

Yes. Thank you for sharing your perspective, sharing your story. You can check out more of Melissa's story on @OurRealRareLife on Instagram and see some of her posts elsewhere. But we can't thank you enough for being here. You're a dear friend, and I'm so grateful for you.

**Melissa Schlemmer:**

Yes. Thank you so much for having me.

**Michael Murray:**

Melissa's story was so impactful. The stigma that we're dealing with when it comes to family caregivers in our society, it's just not even something people are really talking about and recognizing.

**Holly Carmichael:**

Yeah. This idea that you have to take care of your own and pick yourself up from your bootstraps, and it's really a bit ridiculous when you look at it in the mindset of what it actually takes to make that work, to make that happen.

**Michael Murray:**

Absolutely.

**Holly Carmichael:**

And look at the lives of the people we're talking about and their experience.

**Michael Murray:**

Absolutely. Well, and so as we always like to do, we end out the podcast, dear listener, with three things that you can do. We're going to give you an individual thing that you as an individual can do. Number two, we're going to give you something that you can do to have a systematic impact. And then number three, we're going to give you an organization to donate to.

So our first thing that you can do is check yourself. What stigmas are you dealing with as it relates to family caregivers? Holly said it best when we were prepping for this. Until you've walked in someone's shoes, until you have been there, I really think that we all have to really check some bias that we have towards family caregivers. As a society, we need to check other people's bias towards family caregivers.

**Holly Carmichael:**

Yeah. And the amazing thing is that you find when you look at research that's been done on self-directed programs that allow for paid family caregivers, the outcomes are better. People are having better quality of life. The programs cost less to the Medicaid system. So we're talking about a better, cheaper option. You would always pick that option if we were talking about anything else. But because there's this stigma that no, you take care of your own family member, you don't get that benefit. It's just not okay, and I think we need to ask ourselves where's that stigma coming from and why.

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**Michael Murray:**

Absolutely.

**Holly Carmichael:**

And look at the actual results that these programs bring in the lives of the people, which really brings us to our second point is that these programs are set up on a state-by-state basis. So each state decides how their Medicaid programs are set up. You heard us talk to Melissa in the program that's set up in Minnesota, which allows for parents of minor children to be paid caregivers. But it's one of only few.

So I ask you to look at your own state programs, your own HCBS 1915C waivers and whether in Appendix E for self-direction, if family caregivers are an option. Many states we saw through the pandemic started to expand this out of need because we needed more caregivers. We needed more caregivers that were within the bubble. And they found success, and we need to fight to keep those changes in place to allow family members to be paid for the valuable care that that they're providing.

Many talk of concerns about fraud and it's just the evidence is not there to support it. I think the real fraud that exists is the unpaid care that's provided is truly what's happening. We need to make sure that that people's needs are being met, and family caregivers is one of the best ways to do it.

**Michael Murray:**

Absolutely. And I think the pandemic allowed for us to change the structure for a period of time and see wow, this is a really valuable solution. So let's fight to keep that in. If you're in a state and you're a policy maker and you're listening to this, stand up. We'll get behind you. The disability community will get behind you.

And if you're in the disability community, and this really brings us to our third piece, which is what's an organization that you can donate to, I'm going to be honest. We had a hard time finding an organization that's stepping out and talking about family caregivers and the need for it, at least making it a bold, forward-facing initiative that wasn't mixed in with something else. There are organizations out there. We're not criticizing anyone. But we do think that as an advocacy community, we need to make this a center point issue, forefront, not mixed in with something else or with broader HCBS funding. We truly believe that this should be a center point of ensuring that family caregivers are something on a national level that is there. There are organizations like AARP that are advocating for family caregivers, especially for older adults and seniors. And we love that. And there are other organizations out there too. And so we don't want to under value that. But we do we want you to step up to the plate.

So all of us that are part of the Disability Garrison, we're going to fight for this. We believe that there is a future wherein family caregivers no longer have the stigma that they experience today, and that those who are most qualified for the job can step up and do it and that we can create a system wherein they're getting paid for that work. And we see it as incredibly valuable to the person with a disability, to the family that's being served, and to the broader system in which we work in.

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**Holly Carmichael:**

Yeah. You should get to choose. It's your life, your choice. You should get to choose the most qualified person to be paid to provide your long-term services and supports bottom line.

**Michael Murray:**

Your life, your choice.

**Conclusion:**

Thank you for listening to the *Disability Garrison Podcast*. My name is Amber, and my son Blake directs his own services in North Carolina through GT Independence. What we like most about directing our own services is having the freedom it allows in our life in every way. For the links and resources mentioned in this episode, go to [GTIndependence.com/podcast](http://GTIndependence.com/podcast).

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