Participants:

Holly Carmichael Michael Murray Tony Coelho



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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.

Welcome to this special edition of the Disability Garrison. Holly and I recently had the pleasure of interviewing my dear friend, the honorable Tony Coelho. We had such a great time and covered so much with him that we're going to actually be releasing three many episodes through the month of February, and it's going to lead up to the fourth episode, which is all going to be talking about the Americans with Disabilities Act. So if you don't know a lot about the ADA, don't worry. You will, and it is going to be awesome. This episode is the first of the three mini episodes. They're going to be a little bit different than our normal structure. Usually, we present our listeners with a problem, and then we give you some actions that you can work towards the solution. But for this episode and the next two episodes, we're going to be listening Tony as he talks about various parts of his life and leading up to the signing of the Americans with Disabilities Act but also just recognizing what does it take to be a leader that can make a substantial change in the world. Also, I wanted to tell you we're going to be holding a contest on the GT Independence Facebook page this month all around the ADA. It's called the I Can Campaign, and we're looking for listeners to submit how the ADA has had an impact on their lives. So for more information, go to GTindependence.com.

So without further ado, here's Tony Coelho. Welcome to the Disability Garrison. I am so excited. I'm always excited, Holly, but this is a special honor. Today we have the honorable Tony Coelho joining us on the podcast. Tony was the former House Majority Whip of Congress, the primary author of the Americans with Disabilities Act. Tony, welcome.

Tony Coelho:

Thank you, thank you, Michael. Great to be here with both you and Holly.

Holly Carmichael:

Yeah. It is an honor, as Michael said. We're just excited. I can't even believe I'm in the same room and can touch you. You're an icon and have done such amazing work for people with disabilities and can't wait to dive in and talk about it today.

Tony Coelho:

Great. Looking forward to it.

Michael Murray:

So where did you grow up?

Tony Coelho:

Central California on a dairy farm. My family, Portuguese. I'm 100% Portuguese. My family comes from the Azores Islands which are islands off of mainland Portugal.

Holly Carmichael:

Oh, they're beautiful. Yeah.

Tony Coelho:

Between Portugal and the United States. They're way out there, and the United States uses the Azores Islands as a defense resource landing and so forth. But they were born there. My grandparents all came from the Azores to California. My mother's parents, her father was a dairyman in cattle business. Her mother came over as a nanny. And then on my father's side, his father came over as a fisherman, and my mother's parents ended up in Tulare, California which is Fresno, below Fresno and so forth. But my father's parents ended up in Monterey, and they came over, all four of them came over in the early teens and met here and got married here in the United States. But my grandfather came over as a fisherman, and his wife, my grandmother, we always call came over, she was the elite one. She came over with a lot of style and so forth and so on.

So we were in central California, dairy farm, milked cows every day. We had 300 cows. And it taught me a lot because you can't get sick, no birthdays, no Christmas. Cows have to milked every morning, every night. And it was a family operation so we didn't have hired hands. So we had to do that and go to school and everything. So we'd get up at three o'clock in the morning, go milk, and then finish in time to go to school. And then get out of school and immediately come home to milk the cows in the afternoon. We'd get in about eight o'clock, 8:30 at night, and then have dinner. And I studied hard. My family basically wanted us to go to sleep so we'd get up in the morning. But I would take a flashlight and study in the bedroom. And my mother would come in and say, you've got to go to sleep. But that just gives you a little bit of a background on that.

So one day I'm out milking in the morning, and next thing I remember, I wake up in a bed. And I'd just had a grand mal seizure in the barn, and my brother carried me to the house and called out the doctor. And the doctor came out quickly. And when I woke up, I couldn't speak but I could hear. And my parents were there with the doctor, and they were talking about what I'd gone through. I couldn't hear what he was actually saying, but I could hear him mumbling and so forth. And what he told them is that he felt that I had epilepsy. I just had a seizure, argued that I'd had a seizure and that was probably epilepsy.

My parents never told me that. They were Portuguese, Catholic, and they believed what the church preached, that if you have epilepsy, you're possessed by the devil. And so we went to two other doctors to see what was going on. My family said, well, it's a lack of calcium. This one thinks it's this, that, but none of them really know. But each one of them was telling them that I had seizure and epilepsy. So then we go to witch doctors.

Michael Murray:

Wow.

Tony Coelho:

And that was a very interesting experience to say the least. You go into a room with really all the lights off, candles burning, pour hot oil on your forehead and on your chest with a candle on your chest. And the witch doctor is praying in some language, and it's as a 16 year old a little scary, a 17 year old. But I didn't, I knew that they were saying that something was wrong, and none of my medical doctors knew what it was, quote unquote. But now I'm going to see if I can get rid of these things.

And so I go to the first one, and it was scary, interesting. But of course, she didn't succeed. So then I go to another one. And the funniest one is I went to this Portuguese man. And so get there, and he speaks broken English. But he basically said to me, take an egg, a raw egg, put it under your arm in your armpit, hold it there for, I forget how long, hold it there for x period of time. And then at the end of that time, take it out, and if the egg has turned black, got rid of the evil spirits.

Michael Murray:

Wow.

Tony Coelho:

Well, the egg didn't turn black.

Michael Murray:

Right.

Holly Carmichael:

Yeah, yeah.

Tony Coelho:

So I said to my parents, I'm not going to anymore, period.

Michael Murray:

Yes.

Tony Coelho:

And my parents were not happy because they really believed that no, I was possessed and embarrassed. They, restricted may be too strong of a word, but they basically did not want me to go in public much. And so we as a farm family, we would take our cattle to fairs and show them and compete. But my mother conveniently forgot to send in my applications, and it hurt. I didn't know why. Of course, I just knew I was still having these problems, but I suspected it was because I was having these problems.

But what it was was that the culture of a lot of Portuguese and other nationalities was that God was punishing the family because of a major sin someone had committed, not necessarily the person having the seizures. But it was for me to have a seizure in public, for the public to know this family had committed a major sin. So that's a hell of a burden for my family, and I didn't understand it at all, of course. And I was, well, as I go through this. But they were going through all this and being told that I was possessed and then embarrassing because who in the family did what and so forth. So eventually I stopped going to witch doctors, and I kept having seizures.

Michael Murray:

I want to draw out two things for our listeners to recognize from this early part of your story. Number one is there are going to be folks with disabilities like myself who listen to this podcast who have experienced some really traumatic encounters with those who love them the most, just like you did.

And for those of you who are listening, there's hope. There is opportunity after this. And I think Tony shows us that through that grit and determination and the voice of God coming and just telling you you're of worth and value and your identity that you can achieve incredible things. But I also think there's a message in here for parents. I think, Holly, maybe you can hit this.

Holly Carmichael:

Yeah. I think parents of children with disabilities can sometimes be one of the biggest barriers without even realizing it.

Tony Coelho:

I like to say that parents love you so much that they handicap you.

Holly Carmichael:

Yeah, yeah.

Tony Coelho:

That's one of my speeches when I talk to parent groups. I just said, my mother loved me so much that she hurt me. She didn't think she was hurting me. But she hurt me in so many different ways. And I tell a story which will relate here later about The Washington Post. I wanted to do a story. I'm on Wall Street now. Want to do a story proving that I was not successful on wall street. So they assigned this reporter David. David and I became great friends because we talked about everything, and he submitted the article, long article to the editor. Editor rejected it. Said, the problem is in here is that a lot of this is based on Tony's epilepsy and the relationship with his mother and father. And you haven't talked to them. You only know what Tony says. And so I can't go through approve the story without having the parents' input.

So David calls me, and he says, look, here's what's happened. It's been rejected after about seven months. And so he said, it's been rejected. Do you mind if I call your parents? And I said, it's fine with me. I have no idea what they'll say. But let's go ahead. So I gave him the number I had, and he called them. About 45 minutes later, he calls me back. He said, you won't believe this. I said, what? He said, I talked to your mom. She said everything that you say is right, said, we, my husband I only went through the sixth grade. We believed the church, we believed the culture, and we really believed that he was possessed. And we're sorry, and we've never had the opportunity. We were embarrassed to tell him it, but we're very sorry what we put him through.

So he does the story. And so I immediately call my parents and say, I understand what you've said. And I flew out and met with them. And so it's sort of repaired a little bit of the damage. But I'll go further on that because I think it's important to put it in here. So my parents are very proud of me being in the Congress. They're very proud me becoming whip and all that stuff.

So when my dad dies, I don't have much of a reaction because we were never that close. When my mother died, she was the head of the family, and she's the one who made the decisions not to have me do things and so forth. So I'm there, and I'm at the cemetery. And as the body's going into the ground, a voice comes over me and says, you have to decide, do you love her or do you respect her? At that very moment, I go, and I quickly say, I love her but I don't respect her, what she did to me. And I immediately had a seizure right there at the cemetery. And the message that I give to mothers and fathers is that you've got to be careful how you treat your daughter or your son. If you don't give them a chance to participate, you don't give them a chance to succeed.

Michael Murray:

Well, and I think our it's important for our listeners especially the parents out there to know that it is a fine line. We do respect what you guys do. And I've had the privilege of watching a lot of great parents of folks with disabilities including my own and Holly for that matter. And there is that fine line because you are an advocate, and we value that. But you also allowing for that dignity of risk. And Holly, I think you do a great job with Maggie. I love watching you allow Maggie to do it.

Holly Carmichael:

It's definitely hard.

Tony Coelho:

And I know I'm being hard with you right now by saying that.

Michael Murray:

No, no.

Holly Carmichael:

No, no. It's so true. Maggie wants to be a doctor when she grows up, and I want to make sure I don't in any way quash that that's a possibility.

Tony Coelho:

Yeah, it is a possibility.

Holly Carmichael:

It absolutely is. And I was talking with my husband on—

Tony Coelho:

But she'll change her mind several times.

Holly Carmichael:

She will. She probably will. As she does. We were also talking about dating. And she's still fairly young. She's only eight, but some of her cousins are having little boyfriends here and there. And I thought, 'my God, what will I think of her dating someone and how protective I might be over her versus my niece.' And just you have to stop that bias. I've seen so many parents doing it.

Tony Coelho:

But the point is you're right to have that fear.

Holly Carmichael:

Yeah, yeah.

Tony Coelho:

You're right to have that fear, but it's the same fear with somebody without a disease.

Michael Murray:

That's right, that's right.

Tony Coelho:

That's the distinction. You can't over shelter.

Holly Carmichael: Yes.
Tony Coelho: Just because of the disability. Obviously, with her in a chair and so forth, there's certain things that you've got to be concerned about. I understand that. But the people who she dates, they have to respect that. Right?
Holly Carmichael: Yeah, absolutely.
Tony Coelho: But the point is, but that whole struggle for her and dating is what's going to be part of her.
Michael Murray: Yeah.
Holly Carmichael: Yeah.
Tony Coelho: And you have to let that develop, let that become part of her soul and so forth. And it's really important to give that opportunity. But I've had, when I talk about this, I have parents who are crying and saying, well, I do that. I said, well, just understand, there's nothing wrong with what you've done if you correct it.
Michael Murray: Yes, that's right.
Holly Carmichael: Yeah, yeah.
Tony Coelho: As long as you understand that you're overbearing on this and that what you should be doing is giving your son, your daughter an opportunity to live life the best that they can, then you're fine. But I said, just understand what you could be doing and don't do what my mother did to me.
Michael Murray:

That's right.

Holly	Carmichael:
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Yeah, yeah.

Tony Coelho:

Because I tell you what, I still have the scars from it.

Michael Murray:

Yeah.

Holly Carmichael:

Did you ever believe, I'm curious, did you ever buy into this thought that you were possessed in some way?

Tony Coelho:

No.

Holly Carmichael:

No, no.

Michael Murray:

You knew it.

Tony Coelho:

No. I never, I didn't believe it. I milked cows every day, went to school, and got great grades. I was student body president in junior high school. I was freshman class president in high school, sophomore class president. And then I can't remember what else. And then I was student body president outstanding senior. I believed in myself.

Holly Carmichael:

Yeah.

Tony Coelho:

And I had to work hard to do all these things and still milk and everything else. I didn't buy this stuff. And I knew that I had passing out spells, right? And I didn't know what they were. And I just felt that the doctors didn't know. So I was blaming the doctors where my parents were sheltering me from what the doctors told me, right? And in effect, they hurt me more.

But I look back on it and I'm really glad that that happened because if I had known that I had epilepsy, in those days, it was a real problem. And I may never have fought to do what I believed I needed to do if I had fallen into I have it and my parents control because I have seizures and it's not good. So they hurt me a lot, but in a way, they helped me be stronger.

Michael Murray:

Thank you so much for joining us today for the first of three mini episodes with our dear friend, Tony Coelho. We are releasing a new episode every Tuesday in February, and then on 2-22-22, we're going to cap it all off with a deep dive into the Americans with Disabilities Act with Tony. I hope you'll join us again next week. In the meantime, be sure to head to our website for more information on the I Can Campaign. Because of the Americans with disabilities act, I can. We want to hear from you. What has the ADA meant to you? So go to GTindependence.com. Thanks for being a part of the Disability Garrison.

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