



Season 4 | Episode # 27

How to Advocate for People with Disability and Dwarfism

Angela Muir Van Etten

Crystal Keating:

I'm Crystal Keating and you're listening to the Joni and Friends Ministry Podcast. Each week we're bringing you encouraging conversations about finding hope through hardship... and sharing practical ways that you can include people with disability in your church and community.

An advocate is someone who pleads the cause of another, one who helps defend, protect, and comfort in a time of distress, and as a dwarf of three feet, four inches, Angela Muir Van Etten has spent a lifetime advocating for herself and others as equal contributing members of society. Angela is a dual citizen of New Zealand and the United States and qualified as a lawyer in both countries.

She's also served as national president of both Little People organizations, and she's joining us to talk about her experience as a disability advocate and offer hope for changing the discriminatory treatment of people with dwarfism and other disabilities. She shows how advocacy makes change possible when people call out what's wrong, care enough to stand up for what's right and have confidence in God's power to change hearts.

I love that. Welcome back to the podcast, Angela. It's great to have you on the show today.

Angela Muir Van Etten:

Thank you. It's good to be here.

Crystal Keating:

Your life has really been marked by advocating for positive change for those who live with disabilities, no matter the size of the task, and often it is a big task.

So early on, what were some of the ways you sought to change societal attitudes and create a more accessible world for people with disabilities? It really is a change of heart and world. You know, it's both of those things. So how did that start for you?

Angela Muir Van Etten:

Well, I think for me, early on was probably more focused on self-advocacy. I was waiting for my own place in the world. I was learning to speak up for myself. I had to reject discriminatory attitude of people like employers, potential employers, people that I met who were hung up on size and they couldn't really see what I could do.



And so, I was in the beginning really demonstrating that I was capable as anybody else. And the shift to advocating for others came in 1981, and that was the International Year of Disabled Persons, and I decided to apply for a Winston Churchill Fellowship in New Zealand where I grew up and was still living there.

And that brought me to the United States, and I was awarded the fellowship. And I came to the US for three months to study public education programs to improve attitudes towards people with disabilities and legislation to protect the civil rights of people with disabilities.

Crystal Keating:
Oh, amazing.

Angela Muir Van Etten:
That's what got me going because I toured much of the country and visited 40 different disability organizations, was really just immersed in the disability culture.

Crystal Keating:
Right, right. And you know, when we think about societal attitudes, what are some of the things that stand out to you? Just the way that we view people who are different from us.

Angela Muir Van Etten:
Well, people think of us as less than. You know we don't wanna give you the same opportunity. They'll just push you to the side. They think they're being nice. They'll say nice things to you mostly, you know, when you're in a formal setting, like a job interview or something. But they just can't imagine you being able. Of course, not everybody does discriminate. So, you just keep going and persevere until you find someone who will take you for what you can offer.

Crystal Keating:
Right. Oh, that's so important. You know, we just talked to a woman who was a medical doctor and she practiced for many years as an internal medicine physician.

And after three bouts of cancer and surgery, she lost her speech, lost her ability to talk, and through surgery, her face became disfigured, as she would say. And people stopped taking her seriously. And she said it was the first time that she felt unrecognized, even for her intellect. I think they assume that she didn't have, you know, the mental capacity to interact.

And so, I can see that the, the way that we perceive others really is such a barrier to like really a full life, just like you.

Angela Muir Van Etten:
Yea. It truly is. And even now, when we have the laws that protect people from discrimination, most people are not silly enough to actually say what they're thinking, but they, they hide their attitude.



But you can tell, you know, right away whether a person is willing to take you seriously. And because, you know, they won't look you in the eye. They don't ask proper questions. And so yeah, you just have to find a way past those people and trust that God's going to give you the opportunities that you need and also not be knocked back.

It can be discouraging. You know, I'm not one to file lawsuits. Things happen all the time where I could have filed many lawsuits in my life, but that's not the way I prefer to put my energy, not litigating whether or not this person, you know, discriminating.

But there are times of course when it's so extreme that you really have to challenge them with the law that's available. But so far, I haven't had to do that. My advocacy is actually a lot of it has had to do with, actually helping to mold the law and be involved in creating laws that make extreme behavior towards people with disabilities unacceptable. And that's some of the things that, you know, I have worked on as an advocate.

Things like dwarf tossing and also the environment is so inaccessible to people with disabilities, not just dwarfism, but anyone who has a problem reaching things is severely challenged to be independent. And that's of course the goal is to be able to go out and function just like other people can.

Crystal Keating:

Right, right. And you know, this is something I hadn't thought about, but talk more about the physical accessibility. We know about ramps and curb cuts. What are some of the physical challenges that people with dwarfism face? I didn't even think about the ATMs. That's something you were involved with, right?

Angela Muir Van Etten:

Right, right. So, Little People of America appointed me as their delegate to represent them on this committee which is called the A117.1 Committee, which it's one of the 13,000 American National Standards Institutes committees that write standards for every industry, and so Little People of America was invited to apply for membership because the ATMs were coming in and then automation was just beginning back in the nineties. Instead of things getting better for us, it was getting worse because there were no people to serve you. You had to be able to serve yourself. But everything was outta reach. And so that created a huge problem. So, I went in on behalf of Little People of America, or as many people call it LPA as the delegate. This committee was charged with writing a standard for accessible and usable public buildings and facilities.

And the standard is revised every five years. And so, I came in with a proposal to lower the reach of everything actually that needs to be touched, pulled, turned. And so, ATMs were kind of the catalyst for little people. Okay, we have to be able to reach ATMs, but little did I know until I got there, that the way it's written, you don't just come in and say, I wanna change the height of ATMs. We came in and I found out that it's a general provision and the standard that affects anything. And so, it's ATMs, elevator buttons, gas pumps, fuel, you know, dispenser units. Window latches, door handle lights, you name it, is affected by this provision that we went in there and said we couldn't reach it.



And of course, the people in there, they were sympathetic, but not wanting to make a change. And it was really like a David and Goliath situation because we were up against, LPA was up against the banking industry, building owners, and the energy sector, you know, the people who put out the gas pumps. I mean, they were all opposed to making any changes at all.

And of course, we as little people didn't really have a huge population. There's only about 30 or so thousand, 30 to 50,000, you know. There's no census numbers on it, but based on how frequently dwarfism occurs, it's probably about that number. So, they were thinking, well, this isn't enough people for us to make any changes.

So, I went and did research and discovered that there are half a million people with disabilities who would benefit from lowering the reach and that's people with quadriplegia, cerebral palsy, people who have had strokes, you know many different people who have tough trouble. Maybe they don't have the height limitation, but they have a reach limitation 'cause they can't raise their arms or reach forward. Once I tied it together with all these other people that would benefit, they had to start paying attention to me. It's a three-year process. I was there fighting this battle and there was actually five debates on this issue over that three years to lower it by six inches.

I call it breaking the six-inch reach barrier. And God was in it, and I knew he had to be. He was in me being chosen to be the delegate. He was in me going there.

I really was like a fish outta water. I didn't know anything about building codes, but I had the background. I had the legal training. I knew the laws. So, it was God's work. He changed the hearts and minds of these people.

Crystal Keating:

Yes. I love that. We can put our hope in him. Well, Angela, if you could break down some of the most important principles and values of advocacy, what would they be?

Angela Muir Van Etten:

Right. Well, the first thing you have to do is to care. You have to care enough to do something and almost to where your sense of injustice is aroused. I even say to the boiling point. I mean, you really have to be hard under the collar about the issue. If you're gonna invest as I did, seven years of my life sitting in these boardrooms with 40 other professionals, you know, hashing all these things out. You've gotta care and you have to be willing to do something.

You can't sit around waiting for somebody else to do it. Now you can say something has gotta be done about this. And then the next point is you have to be ready to make the commitment. Commitment is personal. You can't sit back and say, okay, this is very wrong. Someone's gotta do something about this. And then you don't do anything. We can't expect other people to do something if we won't do anything. I think the next thing that's really important is competence.



I mentioned that I was like a fish outta water in the committee on access and public buildings. But I learned. I had to learn the process. And actually, the chairperson came up to me after a while and he said, wow, you really are learning how this process works.

He said, we have some people who've been in here for years and they still don't know how to do it. So, it's like, I took it seriously. I needed to know how they operated.

You have to know how to present a proposal and argue for it. So, you gotta know what you're talking about. And then you'll also have to know where to go. Who's the one who has the power or the authority to make the change? I sometimes see petitions coming around for signature for some issue that's going on. But the petition is going to somebody who has no authority to do anything about it. And I'm thinking, why are they sending this petition to this person? You know, they've got it wrong. You have to know who can make changes. And then the other thing that's really important is coalitions and connections. You have to network with other people who have the same goal.

I had to get to know the other disability organizations that I've learned a huge amount from other groups in there. And then, of course, you have your supporters. It's another network group, which is your family, your friends, coworkers, neighbors, whoever else. And then communication is the next one. You need to be credible. People have to believe what you say. You cannot exaggerate. Somebody had written something, a letter, and said there were a million little people in America. And then this person came to me from the committee, and he said, why aren't you talking about the million people? And I said because there aren't a million people. I said that's just an exaggeration. That's not true. So, it's really important to tell the truth.

If you want people to listen and pay attention to what you're saying, you have to be credible. You also have to be consistent. You can't say one thing one day, something else the next day.

And this is important too, and that is to anticipate the opposing viewpoint. One of the things I used to do every meeting, 'cause we might be there two or three days, every meeting I sat by somebody different every time and I usually targeted somebody who voted against us.

So, you pay attention to what's going on and I would get to know them, and then once the person sort of knows you a little bit and you know, chit chat, then they start opening up to listen to you. You're not just a stranger threatening their space.

And then of course you have to be willing to take pressure because people are not going to like what you're doing. And so, they're gonna try and get you to change your mind. I think the final one, which it's actually overarching for everything, is to count on divine intervention.

Crystal Keating:
Amen.

Angela Muir Van Etten:



Because we can do everything right, but none of it's gonna matter. None of it will help unless God is in it.

Crystal Keating:

Yeah. You know, and Angela, I imagine that we do have some lawyers who listen. But the majority of the people who write to Joni and Friends are simply trying to advocate on behalf of their loved ones. Maybe they're not in court. Maybe they're doing petitions and a lot of them feel inadequate or frustrated, maybe stuck. Have you ever encountered that? And how did you push through that? How did you overcome those feelings when maybe you felt like you weren't making any changes or progress? I really wanna speak to the heart of the caregivers or the parents or, you know, maybe someone who's listening who feels like I don't even have an advocate.

Angela Muir Van Etten:

Right. You know and that happens to everybody. And I certainly felt inadequate a lot and frustrated cause people don't always do what they say they're going to do. So, I always had to come back to knowing why I was there, to remember my calling. I'm called to do this to be the advocate.

So, trust God to take care of it, not fret about the result. If you know you're doing what God wants you to do, we don't know how it's gonna turn out in the end. And so just keep praying and just keep pushing forward. Just know why you're there. Don't give up. Just pray for God's intervention and wisdom. Because sometimes like, okay, what is the right thing to say here?

You can't get people to do things by making them feel guilty.

Crystal Keating:

Yeah. Just remembering, for those who are listening in, advocating on behalf of someone else. I think it's tiring because there are a lot of barriers and you do have a lot of setbacks, and to remember that God is with you and that he will go before you and to pray and to unite with others who are sharing that similar battle.

You know, and I even think of maybe some listeners today who are living with physical, mental, or emotional challenges. And they've encountered wrongs that need to be righted or misinformation that should be corrected. So, Angela, can you share some encouragement for those who want and need an advocate in their life? How do they find someone like this?

Angela Muir Van Etten:

So, there's a network across the United States for Centers for Independent Living, and this is a federal network that's set up under the Rehabilitation Act. It all started in the 1970s and it's still active. It's still funded, and it's very, very important. And advocacy is one of the core services offered by Centers for Independent Living. So, you need to find your Center for Independent Living that some of them, you know, cover a big territory, but they try to have satellite offices that you can at least get to.



And of course, with the pandemic, a lot of them really have gone to virtual meetings and things so you can get a hold of people even if you can't physically get there anymore. And then there's another network of disability advocates called the Protection and Advocacy. They're kind of like a higher-powered group of advocates in that, many of them are attorneys. They often file lawsuits. And, you know, they also are involved in writing, giving comments to federal agencies when they're updating regulations.

Right now, regulations are being amended for self-service kiosks. And there's a huge problem because, again, it's like the ATMs. Things are going even more automated. You know, a lot of supermarkets and places, they're doing all this self-service at the airport and places like that.

So, they are calling for public comments, and the Protection and Advocacy agencies that are also in each state would be on top of what's going on in that regard. They'd be following the federal regulations.

Crystal Keating:

Well, you know, I'm glad you talked about how our listeners who need an advocate can look into some of those key organizations. And for those listening today, who feel a draw to be an advocate for others, they're not trained as a lawyer, but they want to offer wise and caring assistance. Maybe they wanna be someone who will stand by when times are tough and be a source of strength when weakness comes, just like the Lord is for us. What encouragement would you give to train or prepare the next generation to be an advocate?

Angela Muir Van Etten:

Well, it's kind of like the same principles as I shared in the beginning. You have to care; you have to be willing to make the commitment. I would say that if a person has not advocated in the past, then they need to do some reading on the subject because there is so much to learn.

And it, it actually can be very encouraging to read what has happened, what can be done. Things that have appeared impossible, that God has changed.

Crystal Keating:

Well, there is so much work to be done and I just think of, you know, my many friends whom I've made over the years here at Joni and Friends who would love to have someone stand by them.

And you know, if you're listening today, you're part of a church and you feel the call to do that, or you feel that you need that, I would even connect with your church and your community to see how you can begin doing that. I think at the basic level, especially if it's relational, it starts as a friendship.

Getting to know the person. What need can you meet? Something as simple as filling out an application for someone for insurance or helping them understand just some of the medical decisions they're gonna have to make in the future. I mean, those are some of the very basics of advocacy, even before you get to that legal level. So, Thank you, Angela.

Angela Muir Van Etten:
Can I make an offer?

Crystal Keating:
Oh, sure.

Angela Muir Van Etten:
I'd be happy to give a free promo code for my audiobook, for the first five people that contact. The audiobook for Always an Advocate if they wanna keep learning. I also wanted to share one Bible verse, Galatians 6:9, "Let us not become weary in doing good for at the proper time we will reap a harvest if we do not give up."

Crystal Keating:
Amen. That's a great word. And thank you again for joining us on the podcast today to talk about advocacy.

Angela Muir Van Etten:
Thank you. Thank you very much.

Crystal Keating:
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