

You First Podcast Episode 32: Always an Advocate

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Announcer: Welcome to "You First -- The Disability Rights Florida Podcast."

Keith Casebonne: Hi. I'm Keith Casebonne, and thank you for listening to another episode of the You First podcast. Before we get into it, just a quick reminder, to subscribe to the show, you can simply visit disabilityrightsflorida.org/podcast, where you'll find links to the show on Apple podcasts, Spotify, YouTube, and more.

Today, we'll hear from Angela Muir Van Etten, who just published her third book titled "Always an Advocate." As a dual citizen of New Zealand and the United States, Angela qualified as a lawyer in both countries. She also served as National President of both Little People of New Zealand and Little People of America.

Angela has been a legal writer and editor of law books for Thomson Reuters, a staff writer for the Christian Law Association, and a disability advocate for the Coalition for Independent Living Options.

Her articles on dwarfism advocacy have been published in the LPA magazine, "LPA Today," and online in the "Huffington Post" blog. Angela has international media and public speaking experience, has been interviewed by TV icons such as Phil Donahue, Sally Jessy Raphael, and John Stossel. I'm very excited to have her as my guest today. Let's get started.

Hey, Angela. Thank you so much for being our guest. We're excited to read your new book, "Always an Advocate." I like to start off with a question about that. It seems like it's not a random title. Can you tell us why you chose that and how it describes you?

Angela Muir Van Etten: Thank you. Keith, I'm happy to be here. I've been looking forward to this conversation. The title, you're right, it's not random. It came out of a presentation that I did at a school. One of the questions from a student afterwards was, "How long have you been an advocate?" That really got me to stop and think on the spot. I said, "Always."

I can't think of a time when I was not an advocate. Always an Advocate came together as a result of my experience. I'm an advocate ever since. There are moments in your childhood that stand out. I remember being in school. The kids were running out into the playground, and I got left behind. I stood at the door of the classroom and said, "Hey, wait for me!"

Right from the beginning, I remember having to advocate for myself to not be left behind, not be overlooked, and as an adult, being always advocated for myself.

You can be standing in line where there's no, not like in a bank where they put markers where you should stand, waiting to get served and people jump ahead of you. They think you're a kid with the other adult, to speak up and say, "Excuse me, but I was ahead of you." "Oh, I'm sorry." Not everybody says they're sorry.

Just to advocate to get help, somebody pass you something, job interviews, you name it, I'm always advocating about something. It started with self-advocacy. That's how it describes me. It moves on, as you get older, to advocate for other people. As in the organization for little people would call me for advice and I would give them guidance.

Then, I had the opportunity, which I'm saying "had" since I have now retired from my paying job. I don't call myself retired, but I'm older now. I had the opportunity to be a system advocate. I was working for people for the Center for Independent Living advocating for them for personal issues, then get to education, then benefits, whatever.

Also, systems advocacy for county school boards, county commissions, elected officials. I mentioned already, Little People of America, I advocated as a volunteer for issues that will come up shortly in our conversation, I'm sure.

Keith: Indeed. Do you want to talk more about your book? I did want to mention that you've written two books prior to *Always an Advocate*. If you could tell us about those two books briefly and your journey of writing over these last 30 years?

Angela: I first got the idea to write a book when I was a young adult. That one was "Dwarfs Don't Live in Doll Houses." I was a single person. I planned the whole thing to cut off before I did get married later. Even though I finished the book after I was married, the book sticks with my perspective from a single person. It's from birth through to young adult. That was the first one.

There was a long pause, 32 years, before I got to the second book. The second book is "Pass Me Your Shoes." That one is a short-hand, call it, our marriage story. That one came out only a year ago. People actually wanted that book because when I had written the first one, I went beyond, my perspective was from a single person.

I continued on, after I was married, talking about issues related to dwarfism. Robert, the person I married 40 years ago, this one, he was in the book as a little person, and also he was the president of Little People in America when we met. People were expecting to read about him because they knew I was married when the book came out. They were disappointed.

They said, "Oh, we were expecting to read about your getting married." It was quite a surprising story because I had come from New Zealand on a fellowship. The whole thing was a whirlwind. Of course, the international marriage and immigrating here to the United States. So, we would say, "Oh, well. That will be book two." Well, book two was 32 years in the making.

There were a lot of things that came along that diverted me, shall we say, or detours as well it in the subtitle "Navigating Life's Detours" is part of the subtitle for *Pass Me Your Shoes*.

One of them was, of course, meeting Robert, getting married, immigrating to the United States, having to go back to law school, getting involved in LPA leadership. The final one that got in the way was heart surgery. I had to have an aortic valve replacement.

Then, after that, I was able to go back to work. Successful surgery, that was eight years ago. I no longer had the energy that it takes to work, be involved in church and write. When I retired is

when I wrote Always An Advocate. That was my plan when I retired after [indecipherable 7:04] birthday.

[laughter]

Angela: I said, "That's it, honey. I have to write this book." This third one had been started. That one was detoured by the heart surgery. Yes, it's been a long road. In fact, the original plan was that it should already be a second book, wait for book two.

By now, I had so much material in 32 years, and I had a very good friend, a writer herself, a professor in the university and sociologist. She recommended after she read a banded copy, she said, "You've really got two books in here. It's going to appeal to two different audiences."

She recommended I pull them apart, which I did not want to do with it. It's going to take a lot of I'm getting...

[crosstalk]

Keith: That means I have to write a third book now, oh no.

Angela: Well, it meant I had to separate them and explain the gaps. That's how actually the book Always an Advocate became...I divided it into three parts because I couldn't go chronological. The book entered that I had, she said, "Oh, there's a big gap here." I said, "Yeah, people are going to wonder what happened in between. Well, that gap happened because of becoming two different books.

Keith: That makes sense.

Angela: That why I didn't organize the Always an Advocate chronologically. It's topical.

Keith: It is. That makes it unique, and a very interesting read, I found, which perfect segue. Now, let's talk a little bit about Always An Advocate. You mentioned this is in three separate parts.

Part one discusses the times that either you, or your husband, Robert, as you already mentioned, served as president of Little People of America. What are some of the accomplishments that you and Robert had while serving as LPA president?

Angela: Robert was actually president twice. The first time...They, at that time, was a two-year term. That's when he met me and got diverted in his attraction.

He was a good president, but he didn't really get into the nuts and bolts of what he had wanted to do. He came back as president two years later after having a two-year gap, and worked on getting Little People of America to be a tax-exempt organization.

Clearly, the organization was involved in educational, medical, charitable activities. We have a medical advisory board that volunteers, medical specialists, a lot of workshops, educational workshops on any number of topics that you can think of.

There's grants for scholarships for university, in college, and people are helped, charitable things. We could see that the organization qualified for tax exemption. The funding was needed for the...It was already a nonprofit, but donors couldn't get a deduction for their donations.

In order for the organization to grow beyond just being a volunteer organization, you needed to have that so you could go for grants and to get more staff. We only had one paid staff member who was handling membership and a lot of phone calls.

Now, it's still not a heavily staffed organization. There are three and a couple of people that are paid a stipend for their work. It's primarily a volunteer organization. The tax exemption was a huge thing because it involved having to change the original charter and the by-laws and getting the membership on board.

Among the people who have been in leadership for many years prior to Robert coming along were thinking this is a bad idea. There was a foundation that did funnel money into the organization, into LPA. They held, "the one who holds the purse strings holds the power." Robert's idea was to get it back into the hands of the membership.

That's why he wanted Little People, LPA when they say the abbreviation, back into the hands of the people who benefit. Another thing I noticed when I first came from New Zealand was that the parents didn't get a vote. It's a very interesting organization because it still has for members the parents of the children with dwarfism and the adults with dwarfism.

They're one organization. It's not the parents are separate from the little people, but they didn't get to vote at all. That was changed. They're the ones paying to come and bring their kids to these meetings and traveling across the country sometimes.

The annual conference does move around the country so that more people have an opportunity to attend. Still, that's going to be once in a blue moon that you'll get it close to you. People have to fly to meetings and stay in fancy hotels now. The organization's too big. You need a large hotel with the conference room, banquet hall, assembly rooms, and things like that.

That was the main things that he did. Also, he believed in the members being informed. As I keep saying, LPA cannot run without volunteers. At this time, I'll just get to the numbers, there are 70 local chapters, 14 districts which cover two or three states, and then the national organization. There's many volunteers who are involved in running the organization.

He wanted to keep them informed. He reinstated something that a president many years earlier had. They called it the "Golden Sheet." He wrote once a month a newsletter to the 80 elected people at that time, it's more than that now, just keeping them informed and having people be more involved in decision making. It was a lot of things.

One of the things that happened at his second term also, the dwarf tossing problem came up when he was president. He appointed the right people. Obviously, with his support and involvement, but he couldn't do it all, a lot of people stepped up to help get it stopped.

For me, one of the main things I came in to do, I was the reluctant president because I was trying to write these books, the second and third books.

Shall we say I hesitated to write about it, but it's such a big part of the story. There was a bad season, a period of time, when there was some great people with great ideas, but the way they were being implemented and the way people were being treated was pretty awful.

I came in to bring civility. Let's vary the people and not if you disagree with them, you send them all these swaying emails. When I ran, I was persuaded to run for office. Initially, I was just going to be the membership coordinator. Through a series of events, I became the president to finish out a term.

One of my main goals was to bring civility, where people would treat one another with respect. Doesn't mean we all now suddenly agree, it just means that we learn how to work together. I got things back on an even keel and was happy to turn it back over so I could get back to writing.

Keith: That was interesting part of the book too. I found it fascinating, let's just say, the disagreement that was going within LPA at the time. You had some hurdles to get through. It's a really interesting story.

Angela: It was hard times. Not too many people would have hung in there. I actually felt like it was a calling for me to do it. As a Christian, I felt obligated. The organization is too valuable to let it be taken down by some people that were very hard-hitting, running it like a corporation and other peoples' opinions didn't matter. That's what was happening.

Then, there's always people who jump on the bandwagon. There's none of those people that I wouldn't be happy to sit down in a room and have a conversation. I'd be happy to see them. We got through it. The organization is doing very well today.

Keith: Excellent. You mentioned dwarf tossing. That is what part two is all about, of the book. I remember hearing about that maybe 15 years or so ago. I live in Florida. I'm aware of things that were going on here to some degree, but I had no idea the history of it or how far it goes back. That is a global issue. The idea didn't even start here in America.

Tell us a little bit about how you helped to stop dwarf tossing from becoming as prevalent as some people seem to want to make it.

Angela: Thankfully, I can say that's in the past as well. Yes, it began in Australia. It was a bar room...They come up with crazy things to do to attract new customers back in 1985, the first I heard of it. I actually got a call from a reporter. I'm just thinking back to that. There was something that I had been doing. I thought of the role of some of these reporters.

I got a phone call out of the blue asking me for comments. I couldn't believe my ears. "What do you mean they're throwing dwarfs?" They were doing it for entertainment. I was right back at the first book, *Dwarfs Don't Live in Doll Houses*, I did include a chapter on dwarf tossing. Some people didn't understand why I did that.

I had used it as framework for how do you advocate and make change. That was, I was thinking, only going to be an example of a problem that I thought was going to go away. In that case, with after Australia I was talking about, we had an unfortunate run-in with a nationally syndicated columnist, Mike Royko. Anyone who knew anything about it, his name is not a good one to say.

He titillated people's thinking about dwarf tossing and, "Oh, I wonder if that would take off here in the United States." You could tell he was making fun with it. It was very discouraging. We, people at LPA, got riled up about it. He wrote about four comments over time. He actually aroused enough interest for a local buyer in Chicago, because he was based in Chicago, to advertise a contest in Chicago.

We, under Robert's leadership, [indecipherable 18:09] events stopped and got a PR thing going, a community organizing, bringing together all organizations. We actually had a member at the time, he's still a member, Craig McCulloh, who worked for a legislator, a state representative in Pennsylvania. He knew how to organize.

Long before I even learned to do it, he knew how to do it. He pulled together all the different groups in Chicago, all from the district, to stand against it. Including the mayor's office, we had members of LPA writing letters and making phone calls.

We even got the attention of, at that time that was mayor Harold Washington, who put out a puppet. He put out his own press statement against it. At the time, our community organizing public relationship that was enough to stop it. The bag shut down...not shut down, but the contest were shut down.

It was enough during that PR burst, but the idea keeps spreading. I went to Philadelphia in 1986. In 1989, it popped back up in Florida. When I had written a chapter of Dwarf Tossing I said, "Well, it's public relations if the buyer or the managers of business and the buyers never cared about what bad publicity, it may need to go to the legislature to stop it."

You mentioned hearing about it in Florida. 1989, is when it was so bad that the manager's office would take him to contest from town to town. The local people were bringing it to their county commission, but they've moved on to the next town by the time they had a meeting. They had to go to the state.

I wasn't living in Florida yet, but they had read my book and that chapter. They said, "Well, we think we've got to the place where we need legislation because they're not responding to our attempts to stop it. That's from public relations pressure. Because I had written the book, you know how it goes. I was invited onto a TV program with them. I think it was -- you have it -- Sally Jessy Raphael.

They got that bill passed in Florida to ban dwarf tossing in licensed establishments. It's a very narrowly focused law because otherwise it would be tossed out as too vague, too general, whatever, unconstitutional. It had to be very targeted to a specific problem, and where it was happening.

People could actually, if they wanted, go out on the beach and throw dwarfs. Of course, it's the environment that gets people willing to do it, too much alcohol over a crowd, getting the crowd wound up, and of course the sad part was that there was people willing to be thrown. That did create a lot of conversation within LPA. Well, who are we to try and stop them doing what they want to do.

We had to come up with all these responses to the Libertarian point of view, which I understand Libertarian view points. I announced my opinion and many others, thankfully. They had caused a lot by creating inactivity that was dangerous, number one, because of its skeletal structure of some of it a little person.

They had to [indecipherable 21:52] because they put on a helmet and knee pads or whatever, threw them onto a mattress, none of that was going to help]. They could break their neck. The other part that was scary for the people who are in Florida is that the message that it was sending to the public that it's OK to throw dwarfs.

Then, ordinary person they walked past there on the street, and someone said, "Hey, let me throw you, and then pick you up." You're off your feet before you know it. There was an incident where that has happened, and more than one incident.

This one fellow, he was a businessman, visiting Florida at the time. Somebody did pick him up. He was a sales person. It was very embarrassing for him because he was having this business meeting in a restaurant. I can't remember all the details. I hadn't gone there. I talked to him a few months ago, and especially the kids. You know how kids are.

They get carried away, get bullying. It used to be when I was growing up, I met this one boy who had...In his school, he had been turned upside down in the garbage can, and he couldn't get out. They thought it was funny. A little person's arms are often shorter. Mine are. How, because I'm disproportionate. They're shorter than yours.

He couldn't lift himself out of the [indecipherable 23:13]. They thought that was funny. This is going way past that...Picked him up and threw. It was the crazy people that you had to think about too.

Then, of course, that's degrading, dehumanizing. You name it. It shouldn't be permitted. Thankfully, the state of Florida outlawed it back in 1989. Do you think that was the end of it?

Keith: No, no.

[laughter]

Angela: No. These same people that were in Florida, they moved to New York. They picked up there. Well, little did they know that I lived in New York.

[laughter]

Keith: You were after them.

Angela: I agreed to be the coordinator to get a law passed in New York because they were doing the same thing. They were moving around. I, of course, did media. I wrote to our little...We had this small group, 22 people, that worked on this [indecipherable 24:09]. Well, we got all members involved and city leaders to be our representatives.

There were 22 in the core group that organized to get this law passed. We got it passed, but right at the end, Mario Cuomo, the father of the former governor that just stepped down, he got a lot of flack about signing this law. Thankfully, he came through at the end, and he signed it.

It was a battle all the way to get it. I did go on the "Phil Donahue Show" with the organizers of this, plus two people who got thrown, "dwarf tossees" we call them. The manager was sitting in the audience. One of them was on the platform. I was the only one, at that time, on the platform talking against it.

Half the audience, I think they were college students, the ones that go to the bars, they were thinking they should be allowed to do it if they want to do it. Thankfully, that was 1990, that it stopped in New York. The law passed. That Donahue exposure did help us get the word out. Ten years goes by. In the meantime, I've moved to Florida.

Then some radio station decided they wanted to have a contest. They had this mascot-type person that worked at the station. They got a lawsuit. They filed a lawsuit to challenge the constitutionality of the law interfering with his right to work.

I was irritated more than [indecipherable 25:45] ...

Keith: Beyond.

[laughter]

Angela: ...we had to fight that one. After that, the lawsuit didn't go anywhere. They didn't succeed. Then, 2011, another 10 years go by, and now we got this wild [indecipherable 26:02] . Nobody could believe this. A Florida legislator came and tried to repeal the bill as being unnecessary. That it was historic archive, whatever.

He had [indecipherable 26:16] according to him was getting rid of laws, repealing laws that are no longer needed, like did the law apparently [indecipherable 26:24] still is, but he named it as an example was, "You can't ride a bicycle with somebody sitting on the handle bars." He put this bill in that category. [indecipherable 26:33] .

Keith: Not quite. [laughs]

Angela: We had a wonderful president for LPA at the time, Gary Arnold. He rallied the troops. He put together a team, the people. They did call me. I'm thinking, "Oh, I don't want to do this anymore," but I got in. I was more an advisor then. I did do somethings.

I did get the pleasure of writing. I was offered a opportunity to write a blog post or a Huff post or a Huffington post. What's wrong with dwarf tossing, and so I got to write that, which was really fun to get it laid all out.

Then, there was another fellow who was advocacy chairperson at the time. He put a change.org petition together. He had the brilliant idea...His name is Joe Stramondo. He had the brilliant idea of every time this petition is going to that representative, every time someone signed it, it pinged on his computer.

[laughter]

Keith: The legislators' computers?

Angela: Yeah. We got 4,834 signatures, ping, ping, ping, ping.

Keith: I can imagine.

Angela: On those computers.

Keith: Nice.

Angela: This man, I couldn't believe how dense he was. How disconnected he was from our community. He submitted this bill to repeal in the Dwarfism Awareness month, October.

Keith: Oh, my gosh.

Angela: All little people are cheering, making people aware of what it means to be a little person. You know how to talk to us, whatever, and what we do. Also, you'll be pleased to know, I'm sure, that Disability Rights Florida was one of the people that signed that petition, worked with us, [indecipherable 28:37] with us and fixed.

Keith: Yes, indeed.

Angela: We had a lot of support of letters, Americans Association of People with Disabilities. Their president wrote a joint edit, "Without Little People In America [indecipherable 28:48] Today." It was wonderful the way all that came together. That was building on everything we had won in the previous the case.

Of course, there was a lot of media that came out of all that. The dwarf tossing thing, I don't ever want to hear about it again.

Keith: I'll bet. I'll bet.

Angela: The icing on the cake, we had so many [indecipherable 29:12] I wonder if this guy even met a little person. At the time, I was working for the Center for Independent Living, I was appointed by the governor to the Florida Independent Living Council. I had to be in Tallahassee.

We were going around and sharing our platform and naturally the Florida Independent Living Council added the dwarf tossing, not allowing that bill to pass, the bill was to be blocked, not passed. The repeal, we didn't want to repealed.

I got to meet this guy in his office. He didn't want to talk to us, but we said, "No, we'll wait." He couldn't get out. He didn't have a back door because we were waiting in his lobby. He finally agreed for us to come in. There was about six of us. Robert and I were both there.

Robert is my height, 3 feet, 4. The same height as me. I had to ask him. I said, "How many little people have you met?" His answer, "Well, you and your husband would make it two." He was clueless, absolutely clueless.

Keith: Yes, it sounds like that.

Angela: He didn't know. He would not withdraw the bill, as we were asking him too. He did finally agree to not promote the bill. He wanted to let it die on the vine as opposed to withdrawing it. He probably had a good point.

He said, "But it would have been good for him, anyway." He said, "If I withdraw it, then it's going to come back front and center in the media again." He didn't want that. He didn't want any more media about it. We had to make a judgment call about whether we could accept him saying he wasn't going to promote the bill or not.

I told the team, I said, "Yeah, I think he seems to be legit. He's not going to push it." Plus, we had met with the committee chairperson. We had been assured that it was never going to see the light of day. It was never coming out of committee. It died. It died in committee.

Keith: Good, as it should. Wow, very interesting. Well, and then there's still more because there is part three which covers a wide variety of things all about independent living essentially, access to ATMs, and voting, transportation, and more. It starts with your advocacy regarding ATMs and also gas pumps being lowered from 54 to 48 inches. That's the six-inch difference.

It almost does seem like, "OK, sure, just do it." Of course, that means so many...new construction and all this stuff. Of course, you get a lot of fight, but those six inches mean the world to you. Anyway, tell us a little bit about the early efforts to make that happen.

Angela: OK. Back in '94, there is an organization which has a very long name, and I'm sure most people have heard of ANSI, which a standard sitting organization, American National Standards Institute. They have a committee for everything, just about.

There is one for accessible and use it. Accessible and Usable Public Facilities and Buildings. They have categories of membership. It's not a legislative body, but it operates like one because they write this building code. They have a category for people with disabilities.

Little People of America had never been a member. We were invited to join. Then, LPA had to find someone to be a delegate. Now, I mentioned ability of doing workshops. I used to do workshops in LPA events. I remember a young girl, well teenager, saying to me, "What are we going to do about ATMs?"

I looked at her and asked the Lord, well, Lord, I didn't know what we were going to do about ATMs. That was in the back of my head when I was approached by the president at the time. Ruth Ricker, she came to me and said, "Well, Angela, will you be the delegate?"

Of course, I was thinking, "Oh." My husband, Robert, was saying, "Well, it's going to be a lot of work, and all she's going to get that. They going to put in a lot of effort. I don't know if it's going to change it. They don't want to change it."

He knew from his job experience. I did pray about it. I felt I had. What Ruth said to me, "Well, Angela, if you don't do it, who will?" Now, that's sounds like I'm the only one that could do it. At the time, I was. I had two law degrees. I had all this experience with advocacy, not yet working for Center for Independent Living.

Anyway, and I could write, which is what you need to be able to do. I can talk, which is helpful. [laughs] .

Keith: Helpful, yes.

Angela: I did feel like it was a calling. I went to the committee. I was like a fish out of water, because it's a building code. I know nothing about how to build, the exact code. The members on there were their own little architects and building inspectors. It's all that line of work.

I had never mixed there with people. Of course, I was comfortable with the people with disabilities, not actually knowing all about disability, but I've learned a lot from the other members. We worked together. That was important.

The member from Disability Rights Education Defense Fund, who, sad to say, is recently passed away, Marilyn Golden, she was my mentor in the beginning, giving me the ropes. I watched how she operated, and how she worked the room.

She knew everybody in there. She could tell me who to trust or not to trust. She'd be on it. She had been on there for years. Also, even the people who would never, ever vote with us. I learned how to work with them because they helped me write the code language.

I know how to write, but I don't know how to write building something where it has to be very...that no ambiguity. It has to be very clear. You know how hard it is to write instructions, so imagine writing for building codes.

Keith: Oh, my gosh, right,

Angela: There were a lot of meetings. There was a cycle. They had a three-to-five-year cycle. The cycle was starting. The timing was perfect for LPA to get involved. I was on a learning curve for the first year or two. I always, the whole time, on a learning curve, learning the ropes, even how to operate.

We did Little People of America. It wasn't an organization where you could have troops rallying outside and writing letters and things. All the work happened in that room. They called for public comments. People could make proposed amendments, which is what I did for LPA, propose the reduction from 54 to 48.

Then it goes out for public comment. There was a lot of interest, conversation, but it was insincere. We can sympathize. I know very...not a good word for disability. We're not looking for sympathy. We're looking for change, but then they said we don't have enough information. Is this the right height? We definitely needed to make sure that we had the right height.

Typically, I found out very soon that when somebody was calling for research, it's a code word for delay. In other words, it means we're not going to get to it. Because things had to happen in a certain order, if you didn't get your proposal a round of public comments, then it wasn't going to be put on until the next cycle five years later.

There was a lot of rules and things how this group operates to work. I figured it out thankfully. They thought they had us beat when they said that about the data. I said, "You mean you need

measurements?" "Well, how high can little people reach?" I said, "I could find that out for you." We had a national conference coming up.

Keith: I love this part.

Angela: We set up a table. We put out some M&Ms, or whatever they were, Kisses. People were lined up. We didn't have to persuade everybody to line up. They weren't coming just for the little piece of chocolate. They were coming because they wanted to use ATMs. Of course, it's rolls over, that change, into everything that you have to touch, pull, turn, push.

Which is why the gas pumps were important too because the way the world is going with all this new technology and automation, it was getting worse for little people. You no longer had some guy that was standing outside that would pump your gas for you. I do miss those days.

[laughter]

Angela: They're probably not just for people with disabilities, but everybody. Nobody gets that anymore. Even though they'll tell you, "Press the button and we'll come," here, they don't come. They don't. They can't because they don't have enough staff, with one person inside typically. That button was a joke. I make friends at the gas station if I have a problem. I just ask somebody.

I don't believe this reduction. I call it breaking the six-inch reach barrier. In the book, I talk about this. Probably, way too much tips, I hope not, but anyone who's interested, tips to see how hard this change was. It took years and many debates. One of the key people I persuaded LPA that we needed to be a part of this organization, ANSI, committee was an architect.

He represented, at that time, the hotel and motel industry. He was in favor of this change, but his organization hauled him over coals at the time and replaced him with somebody who voted against it. He is the one who told me, "Don't ever miss a meeting." That's because the way that ANSI works. Whatever gets done one meeting, they could revisit it at the next meeting.

The meetings are going to be usually months apart, but when you have a meeting, it could be three days back-to-back.

Keith: Oh, my gosh, really?

Angela: You're in there at 9:00 AM. They do break for lunch for an hour. Then, typically break at 6:00 PM. You have your evenings to yourself, but you're in there in a big conference room with 40 other people. It's a big square. People are sitting back against the wall as well. I learned from him not to miss a meeting.

I also learned from him and from observing everybody there, how they worked, that you need to collaborate. This change, the six-inch reach barrier that was changed, I don't believe would have happened unless I did my added research to discover that half a million people are using wheelchairs.

With other disabilities, balance issues, and things, they might have length in their arm, but they can't raise it above their head to reach higher than 48. They couldn't fight it because it was on the federal regulations and the comments that they make before they pass a regulation.

Our data from the conference came back overwhelmingly to show that 80 percent of little people could reach 48. We still have left some people out. There are some very small people, and LPA, actually I, myself, in the lower 10 percentile height for dwarfism, but it's going to be hard to get it for everybody unless you get some remote ability to do it, which hopefully technology will bring one day.

Keith: Yes, hopefully.

Angela: We still not all the way there, but the resistance is huge. That was the other reason why I felt that was a calling for me. Not only did I have the education to do this, but also the ability to learn new things, and research things that I don't understand or know about yet.

How to find out was, you have to have the personality. You have to be willing to stand up against people who never be opposed to what you're doing. That's why in LPA, when people were vehemently opposed to ideas, we don't have to become enemies. I saw it working appropriately at the ANSI committee.

People were total opposites, and yet they could go and have lunch. They were friends, and yet, so it was a good experience. Of course, thankfully, and I do believe that it was God's will that He changed people's hearts. Some of the people, I didn't know what they were going to do when it came to voting.

Of course, there were many votes along the way. Some of them I actually confronted, of course, many of them individually. The one who was representing the physical therapists, not physical therapist, excuse me. She was a physical therapist representing the association that works with people with disabilities.

I said to her because she seemed to be siding...She was siding with industry. I said, "I don't understand why you would be doing that. These are the people you're trying to help, and you're not willing to have them change the code to meet their needs." I think that kind of pulled her up short and got her to thinking. She did vote the right way in the end.

Keith: OK.

Angela: That must have had an impact on her.

Keith: Wow.

Angela: I can go on and on.

Keith: There is so much good material in the book. I do encourage people to buy the book, and read these stories. As you were talking, there's some good aspects of advocacy that come up. First of all, to be an advocate, it doesn't mean you have to be an enemy. It means you can still be a friend, but you need to be firm.

Sometimes it even means a little bit of compromise, but if in the end, the results are positive, then you've been successful. The book is interesting stories, I feel like anyone who works in advocacy could read the book and learn a thing or two about how to even be a better advocate.

I enjoyed it and definitely recommend it to others. Now that you published this, I think you said this was your final book.

Angela: Well, I was saying that I'd like to think it is the final book because what follows the writing is the part that I don't enjoy is the marketing.

Keith: Sure. You have to market.

Angela: You have to market. What's the point of getting a book out there if nobody ever reads it?

Keith: Right.

Angela: You got to do some self-promotion, and I don't really like to do that. It's probably people looking when I'm putting out. They think, "Well, she really likes to toot her own horn." I'm not. I'm trying to get people to see what it takes to make change.

Keith: Yes.

Angela: You don't have to give in. People will submit to things that are happening that they don't need to submit to.

Keith: Right.

Angela: Even if you don't win, you still have to do it. That's what I said to Robert. He said about the dwarf tossing, "Oh, you'll never get that." He didn't quite say it that strong. "I hate to see you waste all that time, and it doesn't change."

I said, "Well, I just have to know I'm doing the right thing. I have to try." I don't have to know the outcome. Maybe I don't get it done, but I have to do it. You'll feel good. I was compelled to do it. That's important. You got to have that. You've got to remember why you're doing it. In the middle of it, wow, if you get tired, and you get sick of it.

Keith: I'll bet. Then, again, that's Always an Advocate.

Angela: Always an Advocate. I did something, and one more thing and this is like the icing on the cake. It's going back to this architect, John Salmen. I was saying his name because he's a wonderful guy who's now retired. He had his own business, Universal Design. He understood this from the start about all things are inclusive.

He said, "You know, ANSI forms the foundation for the Americans with Disabilities Act accessibility guidelines which we call ADAAG. He said, "They look to ANSI because of the way they come together and the way that code is written. It's a code that's a model code that then becomes law, and states and local governments adopt it.

ADAAG Federal Access Board looks at ANSI to see if they're going to make changes. The timing was perfect because after the ANSI passed the lowering the [indecipherable 46:07] , ADAAG, the access board was looking at their regulations. They wanted to harmonize because there are differences. That creates confusion.

Again, the federal law and the state law are the same. They did put out a notice of proposed rulemaking in 1999 which included the 48 inches. There was a lot of work that went prior to that that was part of..

Again, LPA went into high gear to get everybody to write a letter. There were public hearings. I couldn't go to all of them, so I recruited people to go to the ones they had around the country just to stay front and center on their mind that there are little people out there that need this.

On behalf of LPA, I wrote [indecipherable 46:51] , 24 pages worth, not just the little letter but compiling everything that had been done in the ANSI, so they could see why the change was made. ADAAG passed it. It went into ADAAG. Now, it rolled over into the federal law as well. That was always the hope, but it wasn't guaranteed. It happened. The timing was right.

Keith: Yes, indeed. Sometimes, a little bit of luck doesn't hurt either. [laughs]

Angela: Well, you could call it luck, or you could call it divine intervention. It's the timing.

Keith: The timing was important.

Angela: I have many [indecipherable 47:40] in the words, but the three things that guided me -- preparation. You cannot go in there if you don't know what you're doing. Even if you're going into a forum that you're not familiar with, you got to learn it.

Persuasion. You have to be willing to find out what the problem is, why don't people want to make this change. Find out, "Why do you think that? What's the problem?" That's why you have to talk to everybody in the committee, even people who are totally opposed. Find out what their issue is, and then you can answer it, hopefully.

My final P...I like alliteration. Preparation, persuasion, and prayer. I really did pray a lot, and I had other people praying. I do credit God for a lot of this. You have to be willing to do the work.

Keith: Indeed. Great stories. If people want to read more of these stories, and they want to find Always An Advocate, as well as your two previous books, how can they do that?

Angela: They're all available for sale on Amazon, amazon.com, in the US. Amazon UK also has it out there. New Zealand is doing some funny stuff right now with the mail.

[laughter]

Angela: It's because of COVID.

Keith: Sure, sure.

Angela: They suspended mail delivery. Anyway, amazon.com, but for the other countries, Amazon, you know you get the co, you have a double extension on it. I also have a blog at my website. I write a weekly blog post.

Keith: What's the address of that?

Angela: Angelamuirvanetten.com.

Keith: OK.

Angela: It's my name. It's the name that author but it's all up close, Angela Muir Van Etten. Actually, the easiest way to pull up the trilogy, I call it a dwarfism trilogy, is to just type my name in the search box on Amazon. All three books will come up.

Keith: How perfect.

Angela: The Dwarfs Don't Live in Doll Houses has been selling for a long time. It's out of print. It has been selling for a long time, second-hand copies with some other person.

Keith: OK.

Angela: The e-book is coming out in December.

Keith: Oh, good.

Angela: Both the second and third book, Pass Me Your Shoes and Always an Advocate are both print and e-book.

Keith: Awesome. All right. Well, I definitely encourage the listeners to check out the books. I enjoyed them. Thank you, Angela, so much for being the guest today. I appreciate it.

Angela: Thank you very much for having me. [laughs]

Keith: Absolutely.

Angela: I appreciate it.

Keith: Thanks.

Angela: Yes.

Thanks again to Angela for being our guest today. Learn more about Angela, read her blog, and find all her books on her website, angelamuirvanetten.com. Thank you for listening to the You First podcast, or reading the transcript online. Please email any feedback, questions or ideas about the show to podcast@disabilityrightsflorida.org.

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