

You First Podcast Episode 64: Global Disability Progress

Maddie Crowley (00:00:00):

You're listening to you First: The Disability Rights Florida Podcast. In this episode, we talk with Rosangela Berman Bieler and Patricia Almeida about global disability advocacy and progress.

(00:00:29):

Hey, everyone. I'm Maddie.

Keith Casebonne (00:00:31):

And I'm Keith, and we're the hosts of You First. In today's episode, we are joined by two international disability advocates, Rosangela Berman Bieler and Patricia Almeida. During our conversation, we discussed the importance and impact of global disability policy and rights work, including their work with the UN and UNICEF. They also discuss how other countries compare to the US regarding disability progress and inclusion, global accessibility initiatives, and the need for continued fighting for disability rights. It's a great conversation and we hope you enjoy it.

Maddie Crowley (00:01:06):

Hello, Patricia and Rosangela. Thank you so much for being on the podcast today. Could you just take a brief moment to tell us a bit about yourself and also provide a visual description of yourself?

Patricia Almeida (00:01:20):

My name is Patricia Almeida. I'm Brazilian living in Florida right now. I have three daughters, one who has Down syndrome and that's why I am in the disability movement. I'm a civil servant, retired, and I'm also a journalist and specialist in plain language or easy language.

Rosangela Berman Bieler (00:01:45):

My name is Rosangela Berman Bieler. I am a 66-years-old woman. I'm also Brazilian. I have black hair and I use glasses as well. I am a white woman, and very big glasses by the way.

And I am also Brazilian and I live in the US for almost 30 years. Started in D.C., then New York, and now I'm in Florida as well.

Patricia Almeida (00:02:13):

I didn't do my description. I am a white woman, curly hair, and I'm wearing some headphones.

Keith Casebonne (00:02:20):

Excellent. Thank you both again for being here. We're really thrilled to have you and have this look at disability representation on a more global level. So you're both the perfect people to talk to about that.

(00:02:33):

I think you've each mentioned that you have studied and worked as journalists. Can you tell us a little bit about how maybe your practice, your experience with journalism has made you better advocates for people with disabilities?

Rosangela Berman Bieler (00:02:48):

Me? Okay, I go first. The older goes first.

(00:02:52):

So I had a car accident when I was 18 in Brazil. I was in the first semester of my college where I graduated as a journalist and advertising specialist as well. And at that time, I was starting to engage in the disability, I would say, movement inside of the rehab center in Brazil. And I was already serving there as a public relations and doing the newspapers of the movement, et cetera. And naturally, while I was being developed as a journalist, I had an opportunity to be responsible for basically all the newspapers on disability that existed in Brazil for maybe 20 years or so.

(00:03:50):

And at the same time, I was engaged as coordinator of the movement and many positions of leadership, including internationally representing Brazil on what was the Disabled Peoples' International for the Latin American councils. I don't know when. This marriage of journalism was a very important tool for me to communicate and to promote disability rights in many different fashions. I'm just giving you one example. And here we are.

Patricia Almeida (00:04:23):

Yes, my daughter with Down syndrome was born more or less 20 years ago. And it was very quick that I realized that the problem between columns was not her but attitude of society about her and also the lack of accessibility. And now we call the bad attitude, we call it ableism. At that time, we didn't speak about it.

(00:04:47):

So being a journalist and involved in media, I understood how mass media could help put real lives of people with disabilities in everybody's lives. Like in Brazil, we have the soap operas, right? That 80 million people watch those soap operas. So what we did, and Rosangela was doing that back in the '80s, was we suggested positive and authentic characters to go in the soap operas and in the marketing advertising. And by doing this, we would give a better image of people with disabilities and also people who weren't in touch with other people with disabilities would feel like they were. The soap operas in Brazil play a very huge role in talking about these issues.

(00:05:41):

And back in the '80s, they were talking about AIDS and we call it the positive marketing. And we were working on that and we still do it. We advise filmmakers and we get always, we were promoting people with disabilities, actors with disabilities and screenwriters with disabilities, technical people, and then technical staff to be involved in film and in media or anything, in anything at all.

Maddie Crowley (00:06:13):

Yeah, it's so cool to hear about both of your work. And I know, like you had just both mentioned, the power of media and especially film and TV. We're going to talk a bit more for those listening being like, "What Brazilian soap operas being the way to reach people about disability?" That is such a cool conversation and we're going to get into that a little bit more later in this recording.

(00:06:40):

But before we get there, Patricia, you mentioned a little bit about easy language, accessible language, and how that plays a huge role in journalism and media and just access for people in society. And I was hoping you could tell us a little bit more about GADIM, which is the Global Alliance for Disability in Media and Entertainment. And as you, as the co-founder, what is it? And tell us a little bit about how it's grown over the years, some accomplishments, some partnerships. Yeah, tell us all about it.

Patricia Almeida (00:07:15):

Yeah. GADIM just do, like I said, they influence behind the curtains the inclusion of people with disabilities in media, advertisement. We have been advising productions, like in Lionsgate, we work with Shutterstock for positive images of people with disabilities, and so on.

(00:07:36):

And about easy language, that's the right terminology today. And in the US, it's not very known. People talk about plain language, which is a little different. Easy language is more simple, simpler than plain language. But easy language is an accessibility tool for people with intellectual disabilities. And if you look at people with disabilities at all, when we have 80% of people with disabilities living below the poverty line in developing countries, then every person with disabilities should have this easy language before you have all the description, before you have sign language. This is how we inform people about things like vaccination, things like prevention of illness, of earthquakes. We have to use a language that everybody understands.

(00:08:34):

And that's why, being a journalist, I already was doing TV and so my text was already very simple, but I went to university and I did two or three other courses and now I specialize and I'm an activist for this. Right now I'm in Vienna at the Zero Conference explaining to people how we should talk to people in general about this accessibility resource for people with disabilities and with intellectual disabilities, that is in the Convention on the Rights of Persons with Disabilities, but that nobody talks about. People just talk about sign language, braille, but no one knows about easy language.

Maddie Crowley (00:09:17):

Yeah, thank you so much for sharing the difference of easy and plain language and also highlighting the fact that I think in the States, in the United States, it's something that is still trying to get momentum. And beyond disability, when you think about people who have English as a second language, maybe people who have never learned how to read, different communities can really benefit from that accessible language. So it might've been born out of the need to make things accessible for people with disabilities, but in the long run, it really benefits everybody. And I think that's what's the most important thing for people to take away and start implementing easy language into wherever they work or whatever spaces they hold.

(00:10:08):

And I think one other thing I wanted to highlight in this conversation too, it's like easy language, like you're saying, is the foundation of these accessible things. If you have easy language, that just makes the ASL interpreter's job that much easier, it makes the captioning easier, it makes getting information out easier. And I just know as an org, for a legal org, there's certain language that legal orgs or advocacy orgs have to use in certain spaces, whether that's in a courtroom or something. But when you're actually thinking about the resources that are going to go to folks that need it, we need to take the time to do it. So I know that's something our communications team is striving to do.

(00:10:55):

So yeah, I didn't know if you had any thoughts in response to that, but yeah.

Patricia Almeida (00:11:00):

Oh, also another thing. It's not just language. You mean you can send a message with a video with just illustration so that the core is language, but the way you are going to transmit this message, then it will depend on the public, on your audience, and each audience is different.

Keith Casebonne (00:11:23):

For sure. It's so great that you're driving force behind this, trying to make this a more widespread thing to use easy language.

(00:11:34):

Also, just a quick shout out regarding GADIM and some of the partnerships you all have done. I know you work with Dom Evans and FilmDis. He's been a guest on the podcast. Beth Haller is also a co-founder and she's been on the podcast, so it's really great. Maybe we're finding the right people, but it's really exciting, the work that y'all are doing. One of our favorite topics to talk about is accessibility in media and the movies and TV and things like that. So yeah, that's really cool stuff that you guys are doing.

(00:12:03):

So Rosangela, you also were very deeply involved in a global initiative that you were actively involved in the creation and approval of the United Nations Convention on the Rights of Persons with Disabilities. Can you tell us a little bit about that and some of the impacts that it has directly on people with disabilities around the world?

Rosangela Berman Bieler (00:12:22):

Yes, it was really a privilege for me. It was when we started negotiating the convention. Before this even, I was already living in the US and I established the Inter-American Institute on Disability and Inclusive Development at that time. And we started collaborating in this process through the Institute. I remember that we received a call from a member of the board of the Institute that used to work in the United Nations in the US mission, and he's a blind guy, and he called saying that their ambassador received an idea about creating a convention on the rights of people with disabilities, and they were needing support so this could get into the discussion in the General Assembly.

(00:13:17):

So we sent letters. We did not have social media at that time, and we sent letters all over the world in Portuguese, in Spanish, and in English to all the disability organizations and the community and missions in the world asking for this to be considered. So it was before the beginning. And then I had the opportunity as the Institute, as we are talking about journalists, we had a list on email at the time. It was something very advanced. It was a community already of all the Latin American organizations of persons with disability. And we created a network that would have generate access to the information that what was happening in New York in every meeting of the convention to all these people that could not be in New York. And we did it for the first two, three years. The process of the convention took almost six years.

(00:14:17):

And then after this, I started joining. I was hired by the World Bank as a disability inclusive development specialist, and I was sitting there with Judy Heumann representing the World Bank in that discussion, that for something, I was in the right place with the right people in the right moment. And so it was amazing we could even bring the concept of inclusive development for the convention, something that was still pretty new.

(00:14:47):

And today, I think we have 189 countries that ratified the convention, plus the European Union, which never before ratified a convention like this. It's something very impactful, for sure. All the countries that ratified, unfortunately the US is not one of them, but all the countries which ratified had to develop their own legislation structure, infrastructure, councils on disability, funding for disability, government programs and things like this, and the awareness gets much greater than what it used to be.

(00:15:31):

So I think the impact is really amazing. And I could even say, in 2011, one consequence of the convention, I was hired by UNICEF as the first senior advisor on disability that they had. It happened all over the world in many different senses. In many cases, maybe the community was not ready for something like this. And today, I think yes, that's true and there's a lot that we have to do to keep the movement as it was known as an individual and groups and collective movement for social rights. What is the version now with social media and with all the easy communication and access to information that people have, but not necessarily the maturity, the discernment to know what to do with it and how to use it for its own benefit?

Patricia Almeida (00:16:31):

I wanted to add that when I speak to American people, they say, "Oh, we don't need the convention. We have ADA." But the convention, it was based on ADA, but it's much more progressive. It has sexual rights, it has Article 8, which talks about awareness-raising, which you don't have in the American legislation. So there are a lot of things that would be beneficial for Americans with disabilities. And I don't see a movement of Americans with disabilities, because in Brazil, we had to, I was part of a movement to ratify the convention. It wasn't easy and we put it into the constitution of Brazil.

(00:17:16):

It was a lot of hard work, but it was really worth it because now it's like the constitution. Inclusive education, for example, I was talking about the soap operas. Before the convention, people with disabilities would go to special schools and nobody said a word about it. And after the convention and the soap operas that we were helping be put on air, people understood and there was legislation behind us to put every child with a disability together with everybody. And if you want inclusion, it has to be from an early age and with accessibility.

Rosangela Berman Bieler (00:18:00):

Sorry, I followed closely, even because of Judy, the strong activities that the disability organizations had in the US as well to ratify. But this is, I think, you can talk about this much better than I. I think that there's a very conservative way of looking at UN conventions here. It's the same thing with the Convention on the Rights on the Child and others. I think the US right now is the only country that did not ratify. In the world, there's only one more country.

(00:18:32):

But the important thing is how the organizations use, in the US and the world, the convention to empower individuals that have nothing. That's the reality of the majority of people with disability in the world. The ADA here protects the rights of a person with disability and others, and it's a very important legislation. All of our local legislation in the world before the convention was based in the ADA. And I was there with Judy also in the demonstration. I'm proud to say this because another opportunity that I had that the [inaudible 00:19:16] had, and what are the means of we have today of using all these resources and develop them even further to empower people who are not empowered at all and they don't have the basic needs for survival results?

Maddie Crowley (00:19:37):

Yeah, thank you so much for explaining all of that. I have a follow-up thought and question regarding that. And I think as people are listening that might not be as familiar with the UN's Convention on the Rights of People with Disabilities, could you explain a little bit about exactly what that does as far as logistically what that does? And also, can you speak a little bit to why the US doesn't ratify the convention? And also, just I don't know. I think for a lot of things with disability, the US is held to this high regard as being the leader of disability rights to start the convention and have that be where things started off of, but I think it rightfully should maybe be debunked a little bit or just discussed. So I was hoping you both would be able to speak to that.

Rosangela Berman Bieler (00:20:36):

I would like to give an example of one of the articles of the convention that is an article coming from the United Nations, the United Nations Convention on the Rights of the Child that is much older than the CRPD, that talks about physical punishment of children. And both conventions, the CRPD brings this from the Convention on the Rights of the Child to the convention on disability, and talks about the prohibition of physical punishment of children with disabilities, which is super common all over the world a lot.

(00:21:19):

And the argument in the Congress is that of the commission that ratifies international instruments or not, normally not in the US, says that who has to decide about what can be done with a child with disability is their parents, not the United Nations. So I think that's the rationale, and for some reason, they are strong and people go for it.

(00:21:55):

So hopefully, one day people will understand that it's not about the UN. It's not about the UN or about the US; it's about a global convention that looks at the human rights for everybody, and everybody should support the human rights of children with disability that are being abused in all senses with all types of violence. And the convention helps this because some voice can come and reclaim that.

(00:22:32):

The convention basically is like a bylaw that you have for an organization. VPO, for example. And it starts with an affirmation like defining what persons with disabilities are. And each of these, it's not a definition as like a dictionary, it's a flexible definition to include everybody and other disabilities that every day are coming up. So you cannot close the definition of something that is part of the human being. And it can come in different forms, it can be identified or not, et cetera. So I think it was a wise decision. And then it goes through articles that we refer, as I said, to children, to women, to accessibility, to reasonable accommodation, to responsibilities of governments like international cooperation and many other items.

(00:23:34):

Interesting to know that during the development of the convention, there were questions about the members of the committee, the committee of ambassadors that were participating in the development, about why we need a convention specifically on disability if there are so many other conventions on the rights of the child, on the rights of the women, and so many others. And the argument, the important discussion was that nobody talked about accessibility, nobody talked about reasonable accommodations, nobody would talk about things that are very peculiar of this area. And this was what convinced the members to go forward and elaborate around it. And of course, it's very important to say that there is stigma and discrimination against persons with disabilities and name it.

(00:24:37):

And something more that I think it's important is that it was the first time that different areas of disability sat together because this convention was the first UN convention developed with the full participation of the civil society movement. So never before. It was always behind closed doors and the activists or the parents or these people could never join. But this was the first time that persons with disabilities could join. And this was something that made history. And I think that an important aspect is that there was no knowledge in the UN about disability, right?

(00:25:29):

And I wanted to say something, but probably it will come later. It was also about the development, and in which point, the first meetings were just to decide if they would do it or not. So we probably had two or three, two-week meetings in New York. We had two a year to decide if this would be a convention or not.

(00:25:55):

So I think the disability moved the presence of people with disabilities, activists especially was massive. It started maybe with 20 people and it finished with 1,000 in the plenary or around this. Don't take me from the number because... But the proportion was pretty big. And I was saying, now I remember, that it was the first time that different areas of disability really sat together, psychosocial disabilities or different groups. And we had a committee working in parallel in the UN in the same building with the ambassadors to discuss the main points and how it would be in one voice the recommendation of the disability movement.

(00:26:44):

So it was one magical movement, very important because even among the different disabilities, we did not know many things. We did not relate. There were conflicts and there were many things. There were issues related to sexuality, for example, the rights of maternity and et cetera that all the conservative countries or authoritarian, I would say totalitarian countries, I don't know what I would say, but would refuse to include an article like this. And even in Latin America, for example, there are countries that did not ratify because you can ratify a convention with exemptions. Like I read, "With reservations," they say. So you can choose what you don't want to ratify and you can ratify the rest. This could be a good option for the US.

(00:27:37):

But I think that it was a learning process for the global disability movement that really was created from this process, a result of this process. International Disability Alliance was created much later to work with donors to be able to implement the convention, and including in the United Nations, which is all the countries in the world. So I think that's a little bit of the history on it.

Keith Casebonne (00:28:09):

From my own take on it too, I feel like unfortunately, the US is... I think too many of us have a US-centric view of the world. Even our national news, all the 24-hour news networks, 99% of the news is local, but we're one country out of hundreds. And so there's not a lot of

international reporting. There is not a lot of international discussion. It's just not on the minds of your average American citizen I always have thought. And I don't know, that's separate from the politics of it and what the government would choose to ratify or not ratify, but I just always feel like there's that perception that, "Well, this is the US. We can do it our way or we don't need to partner with anyone else or so on." And that's a shame. I think that's completely the wrong approach.

(00:29:04):

But anyway, I just feel like it has something to do with it, just that overarching way that people think here, unfortunately. And it's limiting. It's just not... There's so much in this convention that would benefit us. And like you said, you can ratify with exemptions. Why haven't we? I don't know. I don't really understand that.

(00:29:20):

But anyway, just a couple of thoughts on that, that coming from an American, growing up in an American family, and seeing these things, I just feel like it's just an attitude that doesn't really exist unfortunately within our country.

Rosangela Berman Bieler (00:29:34):

Many times living in the US, I was asked if Brazil was the capital of Buenos Aires, which is the capital of Argentina in reality, and Brazil is the biggest country in Latin America. But we are close.

Keith Casebonne (00:29:48):

Yeah, even our geography is not good. It's bad. It's a shame. It's... Yeah.

Patricia Almeida (00:29:52):

Can I add something about the convention, which is I think it's very interesting. There was a, and Rosangela, please correct me if I got my history wrong, there was a conference about discrimination in Durban in South Africa, and then there was this little paragraph about discrimination against people with disabilities. And it was from this little paragraph that people took it and got a whole convention about inclusion and against discrimination.

(00:30:24):

Then we have to consider that ableism is just like racism. It's a structural problem that we have to face and we have to do something together. The feminist movement together with

the Black people's movements, I don't know what's the right thing to say in English, but people with disabilities are always left behind. And we have Black, peripheric, lesbian, a woman with disabilities, and you have all these intersections, but the human rights movements don't get together. We should cooperate more.

Maddie Crowley (00:31:05):

Hey, everyone, this is Maddie from You First, and I wanted to tell you about a program that's going on right now through Disability Rights Florida.

(00:31:12):

We're collaborating with other disability service providers and local health departments to organize free accessible flu and COVID-19 vaccine clinics across the state. We have many scheduled through the end of April. So to find out more about the dates and locations of the various clinics, visit disabilityrightsflorida.org/clinics.

(00:31:34):

If you need help arranging transportation, scheduling appointments, or have any other issues related to vaccine access, we are here for you. You can call us toll-free at (800)722-8142, or telecommunication for the deaf, (800)346-4127. So be sure to visit disabilityrightsflorida.org/clinics for more information.

(00:32:09):

Yeah, I think that's such an important point. We're not single... Is it Audre Lorde who says that? I'm going to mess that up, but there's no single-issue movement because we're not single-issue people. And I'm probably messing up that quote, but I think-

Rosangela Berman Bieler (00:32:27):

No, what you're doing, it's accepted this.

Maddie Crowley (00:32:30):

Yeah.

Rosangela Berman Bieler (00:32:31):

Intersectionalities are something that today, it's impossible not to consider, and yeah.

Maddie Crowley (00:32:37):

Yeah. So thank you both so much for diving into that a little bit further and speaking to your work globally. I think it's so interesting, like Keith said, as someone who grew up here, was born here, it's just not something we're exposed to, which is just the opposite of also what we're told.

(00:32:59):

So anyways, without getting too much into that, I wanted to circle back a little bit with you, Patricia. If you could speak a little bit more about easy language and some projects that you're working on that you've been involved with where they've benefited from your skills in that area, and then maybe what things are on the horizon with your work that we could shout out.

Patricia Almeida (00:33:25):

Yeah. We are a family of diplomats and we live abroad a lot. My husband is now ambassador and I used to work at the Ministry of Foreign Affairs. Our youngest child, Amanda, she has Down syndrome, and we lived in many countries with her and she experienced inclusion and exclusion in developing and in developed countries. So it's not about money, it's about attitude, it's about how you want this child to learn and how do I do to teach her how to learn?

(00:34:01):

We were in Switzerland and it was the worst country because there was no inclusive school, no schools at all. And she went to a special school and it was so bad that she forgot everything that she learned. And so I had to take her out of school. And by doing this in a critical age, like she was preteen, she was from 10 to 13, it was the phase where she would be learning from her peers and she didn't have any peers because she was in schooling in a clinic with a psychopedagogue. But she learned how to read in French, but she didn't have contact with other kids her age. Her peers were not there, so she couldn't learn from her peers and her peers couldn't learn from her.

(00:34:53):

So when we went back to Brazil, for one side, I was so excited because there we had the inclusive education. She would go to a regular school. But on the other hand, she had no idea how to behave with kids her age. So I thought about making a very easy-to-understand book for her to know what her private parts were, that nobody should touch her if she didn't want to, and what to do in case that happens.

(00:35:24):

So I did this very simple-to-use book, and when I showed it around, people who were working and psychologists who were seeing kids that were abused and helping women who have suffered violence, they said, "My goodness, I've never seen anything so easy to understand." And I said, "Okay, so take it." And it turned out that it worked for any kid and for any family and for any teacher.

(00:35:54):

And so from this experience, it's called I Protect Myself, this booklet, we went to churches, we went to schools, and the text and the illustrations were becoming better and clearer. And we didn't speak about sexual abuse. There's not the word sexual because of the words being more and more conservative. As in Brazil, if you teach these things to children, people say, "Oh no, you're teaching children to do sex." No, it's not sex education. It's education to prevent violence, any kind of violence, including bullying. Because if you teach the child your body is your body, you have to love it the way it is because everybody is different, and then the booklet said... We start with very young children, preschool children. So when you teach about the parts of the body, you don't omit, you don't exclude the penis or the vagina. You say, "Our heads, shoulders, knees, penis."

(00:37:00):

And so when you teach in a natural way, you're talking about your head and you're talking about the other parts. You say that they are the private parts and you say that the private parts, nobody should touch them. And then you said, "Oh, some people have one arm, some people have two arms. So some people don't have arms," the same way about the legs.

(00:37:24):

So if you teach very small children in this natural way and say, "Everybody's different and everybody's skin color is different," then they would learn and you have to respect the others' bodies because the future aggressors are there on the preschool too. So respect the others' bodies, love and protect your body. And then from this experience, we made this guide on how to use easy language, and that's the one I'm launching for the world on how to communicate in a way that everybody understands.

Keith Casebonne (00:38:00):

That's a really fascinating project and something that I agree is needed and not something that... Unfortunately, some people prefer not to talk about or feel that they need to cover it with language that isn't quite specific. But if you're trying to educate someone and that

ease of language and that straightforwardness, I think, is really important. And so I think it's a very interesting use for something like this. I think it's cutting-edge.

Rosangela Berman Bieler (00:38:28):

Can I come in with something complimentary?

Keith Casebonne (00:38:31):

Mm-hmm.

Rosangela Berman Bieler (00:38:31):

Patricia is in Vienna for the Zero Project Conference, which a very big conference promoting important initiatives that are transformative. And today, one of our initiatives received an award as well. We developed in UNICEF the Accessible Digital Textbooks for children. Meaning that in one digital book, you have information in sign, in audio, in written language, simple language. All the exercises and the languages have other resources to facilitate communication that in reality, now it's super possible to be done.

(00:39:11):

We just received the support from a company that does artificial intelligence. That is obviously the way to move this forward because we started this in 2014 in Latin America. Today, we have six or seven ministries of education using the books. They developed their own books with their own culture. And in Africa, three, four countries as well. In Brazil, we tried but it did not happen, but hopefully it will, and it's a solution for every student, not for one. And more. It's a solution for parents who are deaf and have their children that can hear in the school and the parents can support their children with the lessons because they can read, they can understand what is there and so many other opportunities.

(00:40:00):

So I was talking Julie, that it's my colleague that is in Vienna today, I was congratulating. She's receiving the award on behalf of UNICEF. And I said, "Wow, really an idea takes a long time to be validated and then funded." So you have to have a lot of determination and on disability, that happens so much, you have to prove that what you're saying is real because maybe you are not even someone that should be considered you have a disability.

(00:40:40):

I consider this also in the area that we are talking and a big asset that was brought for the modern world, if you can say, that all the schools and every book should be available in digital format that can be easily downloaded, the cost reduced, and all this stuff. It's important for publishing. And then hopefully, we'll advance more and more with this. I hope to be able to continue supporting it in some way as well.

Patricia Almeida (00:41:15):

Yeah, that's a Universal Design for Learning, and I Protect Myself is a little bit about that. The same message is in music and videos and games because each one of us learn in a different way. Sometimes people are better, they listen, and they learn better. Sometimes they read and they have to highlight things. So if you give a lot of possibilities of people to understand and to learn those that contents, the better it is.

Keith Casebonne (00:41:52):

Yeah, agreed. And congratulations, that's really wonderful. Great news.

Maddie Crowley (00:41:56):

You both, and specifically Patricia, mentioned access and inclusion for your daughter. Are there certain countries or certain groups around the world that are really moving forward and leading the way? Is anybody doing work or countries that are doing really good work that maybe we should pay closer attention to?

Patricia Almeida (00:42:19):

What I have to say is it's not about money, like I said, because Switzerland supposedly is the best education in the world and was the place where my daughter was excluded. Places like Italy, since over 40 years ago, they just finished the special schools. Places like Ireland, they're doing very good. Spain and Portugal. The US is doing very well. I lived 10 years ago with my daughter in New York, and it was beginning, it was the Obama's administration. Then I started No Child Left Behind, and then there was federal money into it. And today, she's at high school here in Orlando, and she has all the support that she needs. I'm really impressed. The teachers are amazing.

(00:43:12):

And in Brazil, we have the legislation that doesn't allow you to say, "No, you can't put your child with a disability in the school." The school director can go to jail because of that. But we don't have the money that the US has so we don't have so much support. And

especially in terms of people with intellectual disabilities, what they need is support of others. There's not enough technology to support my daughter. There's someone that has to be there, not all of the time, but some of the time.

(00:43:48):

Of course, now she's getting an AAC device because she doesn't speak much so that she can communicate better and more. But for people with intellectual disabilities in poorer countries where the wages are lower and that you can have a person's help, then the person can live better.

(00:44:11):

But yeah, I went to Venezuela. It was a disaster. No inclusive schools at all. No schools at all. And in Brazil, we have over 100 people with Down syndrome at university, here in the US also with adapted programs. So we are getting there, but we have to push harder and we have to do this in a structured way. The mainstream has to be for everybody because not all students are equal. Like Rosangela was saying, the Universal Design for Learning, it's not just about children with disabilities; it's for every child, and that's the mindset that we have to work with.

Rosangela Berman Bieler (00:44:58):

I wanted to highlight something that we are talking about, money and the possibilities. I think that one thing that is very specific on disabilities and makes life very difficult if you cannot access is reasonable accommodation in all senses. And this costs money. Serious money, serious money.

(00:45:23):

So if you don't have a health insurance because you have preexisting conditions, et cetera, you cannot pay for a personal assistant to help you at home. I live by myself here. My daughter lives in Virginia. I live close to my sister, but I live by myself at home. And just to be able to pay for a reasonable accommodation, I need someone 24 hours a day here. And so the cost of it, if you talk about computer programs, systems, digital accessibility textbooks, right now because it's become cheaper and cheaper, but especially the cost of equipment and AT, assistive technology, and the personnel is something huge.

(00:46:14):

So one thing that UNICEF is working, for example, not only on their behalf, but we started this while I was there, is really thinking on inclusive communities because it's something

that the community has to take responsibility for their members. And there are so many ways, including neighbors giving respite moments for a parent of a child with cerebral palsy, or things like this. So how to solve... And we are not talking about US, we're talking globally. And it's valid for every single country of every single condition or status. The community, to be a community has to include and to support persons with disabilities of that community to be a full member of that community because the issue of who will pay for the devices, for the power wheelchair, for the assistance, for this and that is always you'll take it to a crisis. That's why the name is reasonable accommodation. How do you define this? You don't because it's reasonable for whoever is deciding, right? So it has to be reasonable.

(00:47:36):

So I just wanted to raise this because I think it's one critical point that differs the social movements as we talked before, and justifies even a Convention on the Rights of People with Disabilities because it's not a difficult conversation with anybody when you talk about reasonable accommodation.

Keith Casebonne (00:48:00):

So Rosangela, you've mentioned a few times your work with UNICEF. Can you tell us a little bit more specifically about some of that, what your work as a senior advisor on children with disabilities is, and some of the accomplishments that that work has led to?

Rosangela Berman Bieler (00:48:14):

Sure. First of all, working in a global organization in the United Nations, it's something, it's a privilege to start with, for sure, especially UNICEF, and it's inside of a complex operation always. My post when I retired UNICEF, when you turn 65, you automatically retire, and this was a year ago, and the name of my post by then because so many things happened on disability during these 12 years, my post was called Global Lead on Disability, which means that I was responsible for the agenda as I was before but in the same level, all of the Global Lead on Gender, of Adolescents. Disability started moving to another level right inside of the organization.

(00:49:15):

When in 2022, the day I retired in October, we launched the Global Disability Inclusion Strategy and Policy of UNICEF, DIPAS. That was also a milestone because under my work, I had to supervise and support activities of UNICEF in all the 190 countries that we worked

with. The Accessible Digital Textbooks were in many, in Africa and in Latin America. Now they're going to Asia, et cetera.

(00:49:49):

So it's influencing, guiding, developing support and guidance for countries, but also enforcing it institutionally because there are many competitive agendas, as you can imagine. You have the ones that I mentioned, gender. It's a child first of all, but then you'll have all the other intersectionality, as Patricia was mentioning, the age, the gender. And all of this mean that you need resources to support a new area. And more important, how do you communicate with the 190 country offices that are connected to headquarters, but they have their own program together with their government, that disabilities should be an important part of their agenda with the money that they have, with the knowledge they don't have, and with the priorities that the country has?

(00:50:48):

So there are many different developments in different countries, but we had reviews. I just read the evaluation of the disability program in UNICEF in the last three years, and I was very happy to see how things are going.

(00:51:08):

And for me, just being a very quick snapshot, I think that today, UNICEF... I don't think. That's what is said. UNICEF is the most advanced agency on the rights of persons with disabilities and children with disabilities including, in the whole inclusion diversity, in the whole employment part of it. Many things happened in many different areas during this period and it continues happening. My team is amazing. I continue being in very close touch with all of them. And I think that, again, the convention was a big responsible issue as such, news, in the front that visibility should be considered a human rights issue.

Maddie Crowley (00:52:04):

Well, thank you so much for explaining about your experience with UNICEF. I think these are such important... And I'll just say that in the show notes, we'll be linking to these different organizations and different components that focus on child rights, disability rights, et cetera, so that people can go and learn more about some of the things you're talking about. So thank you so much.

(00:52:28):

It's honestly just, I think I say this almost in every episode, but it just hits me that I'm like, "Wow, I'm talking to these people that have changed the world." So anyways, thank you for everything that you've done. It's an honor to talk with you and meet with you and learn more about it.

(00:52:46):

But as we've touched on a little bit throughout the recording and left on a cliffhanger at the beginning of the recording, Brazilian soap operas, what is the story about this? How are you all connected to it as far as your work involved in it? What is the potential of media to make a really truly lasting impact on inclusion and diversity? Can you just tell us a story about that?

Rosangela Berman Bieler (00:53:15):

Okay, yes. We started earlier. Again, I think that... Well, always the opportunity and being in the right context in the right moment, and in the '80s, this looks like it was three centuries behind us, but soap operas in Brazil, not only they are excellent productions and super well-known all over the world, translated to all the languages in the world, you can see them in the US, in all Latin America and Turkey, in Vietnam and Russia. So I had colleagues in UNICEF because our 10th floor there and all the others, you have people from all over the world, right? It's very international, and everybody was commenting on some actress, or Liz and that person, "What's going on here?"

(00:54:14):

So they have an amazing reach globally and one characteristic of them, they were always less soap, I can say, but much more social engagement in issues that society did not talk about, bringing these issues to your dinner tables every night with the whole family together. So that's what is the media of soap operas. It gets into your, not only into your eyes and mind, but in your house with your family, with everybody.

(00:54:59):

Soap operas were responsible for introducing issues that were, many of them, discussed in little social groups, but never had the outreach that they could have. And for example, as a Brazilian, which is a huge issue or disability rights or gender and all the issue in a Latin country, going to many countries that are very much with a lot of macho approaches, talking about gays and lesbians and putting characters that would be loved by the population, and these issues were discussed at home in that dinner table every night. What else can do this?

(00:55:51):

Even if you think about social media, you go individual to individual and people select what they want. And if they don't select, the artificial intelligence will select for them what they'll see and you'll start getting into a bubble. And you never get out of this, as I have. Even I have people here very close that get into this. You start following one thing. When you see, you're brainwashed.

(00:56:20):

The soap operas are democratic. You can say they're democratic because they represent many different causes and life experiences of people and types of characters, and they don't allow you to even choose because they go to your house anyway. They knock the door, and the door is open automatically. Even if you hated the best soap opera, you will start seeing the new one that will start on Monday. So that's a culture. It's a cultural thing, and it covers many aspects that are important that are not discussed in society.

(00:57:01):

So in the '80s, we had some facilitators because there was a guy who was an important one. He was important because his father was one of the political people that combated the dictatorship and he was dead. He was a journalist, Marcelo Paieda. He wrote a book that he became a quadriplegic, and he wrote a book about this experience, including his own family. And this book became part all the official Ministry of Education books that public schools would have. Everybody read this book. And disability was discussed there, including through the aspect of sexuality, et cetera. Marcelo was 18 also when he had his accident and he broke his neck on a swimming pool jump or something.

(00:58:00):

This generated a book and generated a play, a theater play. And then we got in touch, we were orienting the characters, and we got in touch with the director that was doing a soap opera. And you see the opportunities at film. My husband also worked for many years in Global TV, which is a bigger TV network in Brazil, and one of the biggest in the world. He was a journalist as well. We met in college and we had some access as well as some journalists and things.

(00:58:37):

And then we started approaching them to influence the characters. And then there were the first character in a wheelchair that did not have a covering thing on his leg or things like this. And we started this deconstructing a little bit the typical image of disability and it

happened in two or three soap operas on my time. And then I think that in Patricia's generation, it happened a lot with intellectual disabilities as well. We had characters that were deaf and blind and many different disabilities as well.

(00:59:16):

So the soap opera industry became an ally on every important social discussion in the country, and disability was not different. So Patricia, your turn.

Patricia Almeida (00:59:31):

Yeah. But back then, in your days, Rosangela, there wasn't any actors or actresses with disabilities playing disabled characters. But in the case of Claudina, the first actress with Down syndrome, the first actress with a disability to play a soap opera in Brazil, it was very funny because I knew everything that was going behind the curtains and how people were advising them. But when I saw this woman, this very famous actress Regina Duarte, who played the doctor, she went and said, "This girl is a girl like any other." And my daughter was too. And I began to cry, and I believed her, and I knew everything.

(01:00:21):

So this is the power a soap opera has for 80 million viewers. Of course now with social media, and I mean, with streaming and everything, they don't have as many public, but it's still the subject that's being discussed on Twitter and Instagram. So what we have to do is to take advantage of these stories like this, go again. It's called The Pages of Life. That's the name of the soap opera. And at that time, we had the discussion about special schools and inclusive schools, and we were fighting the special schools that got all the government money and et cetera. And this little girl and the stories behind her helped us lobby for inclusive education because there were some scenes of the mother going to school and fighting teacher. And then she made a statement, "It's her right, you can't do this!"

(01:01:27):

And that was seen by everybody, by the school principal, by the teachers, by the politicians. So it's mass media. It's something that everybody has access to and we, the disability movement, never have this kind of space to talk about things.

Keith Casebonne (01:01:50):

Well, that's just fascinating. I think that's incredible. And I'll be honest, I've never seen an episode of a Brazilian soap opera, but you better believe I'm going to be checking it out

now. I am very curious and excited to watch some of that. And I think it's also incredible where you can see disability representation in places where you may not automatically think that it would make sense or be the right avenue, but this is, like you said, it really was the perfect avenue for not just Brazil, but a more global representation. So it's fascinating. I think it's just an incredible story.

(01:02:28):

Well, thanks again to both of you guys for being here. Let's just close out with what's next for both of you. Are there any future projects or endeavors, things that you want to promote or things where maybe folks can somehow help out or be a part of it?

Patricia Almeida (01:02:42):

I'm happy to say that I Protect Myself will come to the first school in Florida. So I hope it takes the world and we are able to teach every child that their bodies is theirs and that they should protect it and that body is beautiful the way they are, and about the easy language, I'll be promoting it everywhere I go because this is the way, and with the use of cell phones for information, and nobody has time, so easy language is the way to go. There's no way out of it.

Rosangela Berman Bieler (01:03:18):

I'm involved. I connected again with the Inter-American Institute on Disability and Inclusive Development that it's still opened in the US, in Uruguay, and in Costa Rica. The Brazil group is not operating. And we are discussing some interesting activities, training and capacity-building of women, adolescents with disabilities from Latin America as leaders, but it's empowerment broader than transforming people in leaders because it's not like this, but giving the skills and the information that maybe they don't receive as easily as other groups receive.

(01:04:05):

So we are organizing this, including considering a partnership with Florida. It'll be Latin America, but considering Florida, you have such big communities, Latino communities here, and I'm not sure if the girls or the lessons with disabilities here that are in rehab centers or in their communities have as much support as others in their communities. So it can be something interesting. We could discuss this.

(01:04:36):

And I continue doing some consultancies and working closely with UNICEF on some book reviews and different things, and nothing very structured. I am enjoying a lot my time without the pressure of working 12 hours a day and now living in Florida. It would be in New York, I would be freezing. It's kind of freezing here too. But yeah, slowly engaging and keeping connected with the disability movement and community globally in Brazil, in Latin America, and with everybody around the world.

Maddie Crowley (01:05:15):

Well, just thank you both so much. I'm so excited to dig deeper into everything that you shared, get my popcorn ready to watch some really good soap operas, and yeah, keep this conversation going. So I really appreciate your time today and your energy that you shared with us. So thank you both so much.

(01:05:42):

And again, for those listening, we'll include links to things that they mentioned and their work and all that good stuff in and on our website, so you'll be able to find everything that we talked about today so you can learn more too. So thank you both.

Rosangela Berman Bieler (01:06:00):

Thank you so much for the invitation. It was great.

Patricia Almeida (01:06:03):

Thank you for having us. Bye.

Maddie Crowley (01:06:07):

Thank you again to Rosangela and Patricia for being on today's episode. It was wonderful to chat with you and learn so much from both of you.

Keith Casebonne (01:06:14):

Yeah, for sure. Check out the show notes to learn more about the other things we mentioned in the episode.

Maddie Crowley (01:06:20):

And also, please take a moment and hit subscribe wherever you're listening to the podcast. That way, you'll get notifications when new episodes drop. We're on all podcast

platforms, and you can also listen to or read the transcript of each episode on our website at disabilityrightsflorida.org/podcast.

Keith Casebonne (01:06:38):

Thanks so much for listening. Please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org.

Announcer (01:06:47):

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(01:07:11):

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