

Peter Finn: Hello and welcome to PodCatalyst, a podcast dedicated to emerging trends and thought leadership within the communications profession. I'm Peter Finn, executive director of the International Association of Business Communicators, or IABC.

For this PodCatalyst interview I spoke with Anthony DeVergillo. Anthony is a motivated communication professional with a focus in the rare disease space. He lives with Duchenne muscular dystrophy, a muscle weakening disease, but he never lets it stop him from advocating for people with disabilities to be included in society. Anthony is currently concentrating his energy on the social barriers that the pandemic has brought into the public view, such as the need for a virtual option for every in-person event.

After graduating from Rutgers University, Anthony struggled to find a career due to the discrimination behind closed doors to people with disabilities. Amicus Therapeutics was the first to provide him an opportunity to use his abilities as the internal digital communications associate, partnering with employees to unify brand, people and message.

He's also a board member of Our Odyssey, a nonprofit focusing on empowering young adults living with a rare disease with social connection. Anthony is presenting at the World Conference on Monday, June 28, at 3:20 Pacific Daylight Time. The name of his session is "Inclusive Virtual Experience in a Post-COVID World."

It was a real pleasure to get a chance to speak with Anthony, and really looking forward to this session.

Peter Finn: All right. Hey, Anthony. Thanks so much for speaking with me today, I wanted to learn a little bit about you and the session that you'll be doing at World Conference. But if you could just start with, just tell us a little about yourself and how you got into the profession.

Anthony DeVergillo: Hi, so my name is Anthony DeVergillo and I really got into communication, I think it's really due to my rare disease, I have Duchenne Muscular Dystrophy. It's a muscle deteriorating disease that we get to our muscles over time. And living with that disease has really freed a lot of communication barriers for me. So I was always like really interested in communication and how people think and really thinking of ways to get around those barriers. So I went to Rutgers University and got my degree in communications. And after I graduated, it was probably about two years later that I started working at Amicus Therapeutics. I'm the internal visual communications and sending out emails to employees, managing the intranet. And really, what I love about communications is that every day my job is different. I get to work with different people throughout my company. And so, Amicus Therapeutics is all about patient first philosophy and really helping the rare disease and disability community. So I guess my role at Amicus really led to me doing more inclusion initiatives in my personal life. Because I want ... It really started with me supporting the rare disease and disability community. But it really grew beyond that to really including everyone.

Peter Finn: Yeah, and can you talk a little bit about the your topic and World Conference? I don't want to take anything away from the presentation because we want folks to join us at the



conference. But can you just give a quick preview of what you'll be talking about at the conference?

Anthony DeVergillo: All right, sure. So at the conference this year, I will be talking about virtual experiences in a post-COVID world. And I really got into that sort of topic because again, I was already feeling communication barriers. And as I like grew my career and grew into adulthood, I was always trying to find communities online, to be a part of, but most things that I found required me to go in person, which became difficult to me because travel is difficult for me and accessibility ... and just really, there's so much involved in me joining an in-person community. So when the pandemic started and everything started to go virtual, I ... like my entire, like, social life really was positively impacted because I was able to join communities because it didn't involve me going out in person. And last year, I attended the virtual IABC World Conference. And it was just a great opportunity for me to meet other communicators and really get a chance to talk to other people that have kind of thought about the world the same way I do. So that feeling of social connection that was created during the pandemic for me, I want to make sure that that inclusion and that inclusive environment of the virtual world is something we continue to have even after the pandemic.

Peter Finn: Yeah, I agree, I think that it's opened to something, a new way to engage that, that, you know, conferences have never had, you know, the level a lot of conference or many conferences had that kind of access, because it's always been kind of in one format. And, you know, I'm curious to see how, you know, as people can come together in person, how they'll also continue to have that virtual engagement, you know, how critical that's going to be, you know, now that you can have a truly more inclusive virtual event. But I was just curious, what are some things you wish communicators thought more about in terms of virtual inclusivity, and I'm sure a lot of folks have, but what are some things that you'd like to highlight for others?

Anthony DeVergillo: I really want to highlight is something that I call the STACC framework. And that's S-T-A-C-C. And what that is, is really a framework around decisions that are our business decisions. That really puts more focus on inclusion. Because every business has a technology stack, their tools and software that either allows their company to run, or the software and tools that they themselves sell. And I want people to really put more importance ... I want people to understand that the inclusion stack is also important.

And what that acronym stands for is Stories, Technology, Accessibility, Career barriers, and Connections. And really, that's making a decision that creates opportunities for your clients and employees to share their stories, or allows your clients' employees to be more included with your technology, or adding in accessibility tools that help your buyers' employees feel more included. And also, how can you use the resources technology you have to break down the career barriers for your clients and employees? And then finally, how can you make decisions that allow your clients' employees to feel more connected. And I think with that framework, you can make sure that you're always considering inclusion and that it's not a secondary afterthought.



Peter Finn: Are there examples you can point to where you're seeing, you know, organizations getting it, right?

Anthony DeVergillo: Yeah, so for the first part of the acronym stories, I think, a nonprofit that's getting it right is called Our Odyssey. And Our Odyssey is a nonprofit focused on providing social connection for young adults with rare and chronic diseases. And what Our Odyssey did during the pandemic is they really shifted to a virtual meetup situation. And these virtual meetups were really a chance for young adults with rare diseases to get together to really just talk about things and topics that they would only keep to themselves, and really, we're having those virtual meetups, we really, really made new friends. We really created a community and really have been able to definitely ride the wave of the pandemic, because during the pandemic for people with disabilities was a very difficult and isolating situation, and it's definitely true that isolation was for everyone as well. So what I loved about Our Odyssey is, despite the fact that we can't all be together, we can still be together virtually, and be able to share our story, be able to talk with each other and make friends and I really enjoyed that so much that I later joined the Our Odyssey board.

And I guess an example of a company doing right in terms of technology is Poly and what Poly does is makes webcams and practice where I started using this probably webcam recording this podcast on, I really had trouble communicating on Zoom in virtual meetings. Because I have this noninvasive ventilator that to use that makes lots of noise, it would be very distracting but with the technology and Poly webcams — and it's really a technology that they didn't think would help people disabilities. Basically, what the webcam does is it filters out the ventilator noise, which allows me to not even have to mute myself on video calls anymore because you can't even hear the ventilator making noise.

And next with accessibility, a company that's doing it right will be FineTuning. And FineTuning is a SharePoint add on that really like adds a theme and branding to your intranet. But the newest thing that they brought out was something called the Accessibility Tool. And Accessibility Tool has a whole plethora of features related to accessibility. You can turn on colorblind mode, where it would change all the colors on the intranet to the colors that you can see, or you could highlight the titles or have it read you what's on the page. And what I really liked about that is, it wasn't just, oh, let's provide voiceovers, it was providing a tool that helps people with disabilities, with all types of disabilities. I like that they went a little bit further with that.

In terms of career barriers, I probably say who's doing right is called Disability In. And what Disability In is, is a nonprofit focus on promoting disability inclusion in the workforce. And they have this this tool called the Disability Equality Index, which is a series of questions that really helps you understand how you can be more, provide more equality and inclusion for your employees with disabilities at your company.

And then finally, a company that's doing right in terms of providing connection is called Kumospace. And Kumospace is really a new type of video chat. It's something called spatial video chat, where you can all be in like a virtual room. But you only hear people that are within a certain distance from you in that room, which allows you to have 10 different conversations in one virtual space, which is different than all other video chat tools, because you're not all locked



in one room. And I just like what they're doing because it allows me to plan and attend events that are fully virtual, but really feel like they're in person.

Peter Finn: And I guess just on a more individual level, are there things that you're seeing, just you know, some of your colleagues or people that you work with ... in addition to these organizations that are doing this amazing work, what else are you seeing just in terms of maybe colleagues or other communicators?

Anthony DeVergillo: I guess for me there are a couple of initiatives that I'm working on. There's one called the Overjoyed Video Game Accessibility Initiative. And what that is, is my friend and I are putting together an accessible virtual joystick that will allow disabilities to play games on their PC, that normally would require the keyboard, but they only use the mouse. And then I'm also playing the other something called the Inclusion Initiative with a bunch of unified communication, collaboration, companies, like Zoom, Poly and many others. And we're trying to promote that within the communication industry. So what I find is, I didn't really find as many organizations out there as I had hoped that we're working on inclusion and accessibility. So I really just decided to go out there and really connect with the right people to make it happen.

Peter Finn: That's great, I guess, also, just from talking about your session, your upcoming session, what are your objectives for that, when people leave that session, what would you like their takeaways to be or, you know, just some of the things you'd want them to walk away with?

Anthony DeVergillo: I want people to be aware of the needs of their disease and disability community. And I want to specifically make sure that even after the pandemic, that inclusion remains at the forefront of your mind and like in the decisions you make. I really want people to understand that having a virtual option for your in-person event does not mean spending thousands of dollars on some crazy equipment or tool. It's really using the resources that you have to find a way to include people virtually, like for example, if you're just having a small reading, instead of every everybody come to that meeting in person, you can just put a few laptops out and people can stream in from there. And then if you're having like a larger event, I think my session will help you understand the best practices about networking, flexibility and making sure that everyone has a conference or event that they are able to. And also how to engage your participants when it's virtual, because I know we're all Zoomed out, we're all getting tired of the same old same old when it comes to virtual. So what I will share is different tactics to engage your participants, but also continue to make money event.

Peter Finn: Great, well I know that that will be, as you say, folks are pretty, pretty Zoomed out. But yeah, I think any kind of help and assistance, and I certainly need that as well to you know, better, engage folks. So I think, for me, I don't think this ... this has been challenging to always be sort of in the Zoom format for many, many months. But it's also proven to be, I think, quite effective. And there are things that can evolve. And the technology has gotten sort of growing leaps and bounds over the last year, to the extent that we can leverage this technology to collaborate is pretty amazing. So while I'm looking forward to getting back face to face with folks, I definitely appreciate what we've been able to do with the technology and also that it's been able to, you know, help organizations drive their goals around accessibility and inclusion. So, but yeah, I'm looking forward to your session. And I, you know, we always ask this with folks that we talk to on the podcast about, you know, what gets you up in the morning, Anthony?



Anthony DeVergillo: I guess for me, it's kind of a motto that I live by. That motto is despite my disability, my abilities have no bounds. And really like I get up in the morning because I know even though there's barriers and difficulties, I have to deal with that, there is so much I can do, like I can help make the world more inclusive, I can really share my voice. So even as my muscles weaken more and more, there is already something that I can get back. There's always something I can be involved in and really get my team back on really trying to make a difference.

Peter Finn: Well, Anthony, thank you so much for speaking with me and looking forward to your session in just a few days, and hopefully everyone that's listening and will tune in for the session. And again, Anthony, thank you so much for talking with that.

Anthony DeVergillo: It's my pleasure. I'm very excited for everybody to attend my speech at the conference and really excited to do my part to make the world a more inclusive place.

Peter Finn: Thank you.

Again, thanks to Anthony for speaking with me. As a reminder, Anthony will be presenting at the World Conference on Monday, June 28 at 3:20 Pacific Daylight Time. The name of his session is "Inclusive Virtual Experience in a Post-COVID World." And again thanks to Anthony, and we will have more PodCatalyst in July. Thank you.