You First Podcast Episode 28: YouTubers with Disabilities

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

Keith Casebonne: Welcome to You First. I'm your host, Keith Casebonne, and thank you for listening. I hope you have been enjoying the show and encourage you to subscribe to be notified of new episodes as soon as they're published. We're on Apple Podcasts, Spotify, and many of the other places you can find podcasts. We're also at disabilityrightsflorida.org/podcast.

With this episode, we're happy to announce that the You First podcast will also be available on YouTube, quite apropos considering today's topic. This and all past episodes will be there, and they will all include both English and Spanish captions. Our channel is at YouTube.com/disabilityrightsfl, and then find the You First podcast playlist.

They should be available at some point during the week of July 19th. If you don't see them, give it a couple of days and check back again. I promise you they'll be there.

Today, I'm chatting with three YouTubers with disabilities to hear about their experiences sharing their lives, stories, and identities online. They are Annie Segarra, James Rath, and Rikki Poynter. Let's jump right in.

Thanks to you three for being here today. I appreciate it. Let's start off by introducing yourselves and telling us a little bit about your YouTube channel. By benefit of the alphabet, we'll start with Annie.

Annie Segarra: Alrighty. Hello. My name is Annie Segarra, and online, I am known as Annie Elainey. I have a YouTube channel, where I basically talk about LGBT community and disability community. Those are huge aspects of my personal life, so it ends up being personal storytelling and advocacy for rights for those communities of people.

Keith: Awesome. James, you're next.

James Rath: Hi. My name is James Rath. Pretty much, it's where you can find me anywhere online. For YouTube, I produce content that tries to share the experience of the spectrum of blindness and my experiences with travel technology, all sorts of lifestyle things and how I basically get around, which technology plays a big role in that assistive aid there.

Keith: Excellent. Ricky, go ahead.

Rikki Poynter: Hi. My name is Rikki Poynter. I am a disabled YouTuber. I talk about being deaf, primarily. I also have chronic pain and chronic fatigue, so I've included that in my content as well. I'm very known for talking about the captions or lack thereof, whether it's lack thereof as a whole or lack of proper captions, on YouTube, the Internet in general, but YouTube primarily, with my campaign. I call it "No more craptions."

I also do writing on the side. I stream on Twitch as well, whether it's just for being casual, just playing just because, or sometimes I'll talk about the accessibility in so many games that I play.

Keith: All right, thanks. Let's dive in by talking about some of the obstacles you encounter as well as maybe some of your followers, such as accessibility barriers when either trying to create or access content online.

Rikki: Obstacles for me, especially with being a deaf creator, because I mostly speak in my videos -- I grew up oral using English and stuff like that. I speak in most of my videos, and then there's the issue of me trying to understand myself properly so I know where to cut things.

Years ago, when I was first starting, my hearing was better, so it was a little bit easier. Then I'd actually start to caption my own content because in the very beginning -- I know this is going to be surprising to some people, but my content was not captioned.

Granted, I don't know if that was an option that was available when YouTube first started. I don't think it was, or at least it wasn't very accessible to me anyways.

Once that started coming about, then it was like, "OK, I'm going to caption my own stuff," but then obviously that got harder because then I'm like, "Wait a second, what did I say?" [laughs] Even though it's me that I'm trying to read or understand, I have to go off my memory. That makes things pretty complicated, obviously.

Annie: Rikki, I was going to ask about what that was like at the beginning when you couldn't really watch YouTube videos at all without captioning on YouTube and more specifics on what your advocacy was at that point.

Rikki: Oh, yeah. When I first started watching YouTube more seriously, I think it was just mostly makeup gurus because it wasn't nearly as irritating because makeup is supposed to be visual.

It really wasn't the biggest deal unless it was one of those videos where they wanted to do reviews on something because then that becomes more audio-based because they're trying to tell me all this information versus, "Oh, somebody's doing an eyeshadow tutorial. All I need to do is watch you put a brown eyeshadow on your eye."

The one example I use every time because I was watching Emily Noel, and she was talking about concealers, and the actual captions, or auto captions -- you know what I mean -- said, "Cazebras" -- the animal. We're going to put gigantic zebras on our faces, apparently. It was just really, really confusing.

Now things have gotten a little bit better. As I would start to watch more regular vloggers or whatever, things would just become really nonsensical. Our captions have gotten better, but the grammar is still an issue, especially because it goes like this, which is very annoying to look at and listen to. I don't even want to hear it, [laughs] the run-on sentences and stuff.

It's still not even get the accessible show. I was like, "What else can I do?" because I didn't know what else to talk about, and I was like, "Oh, hey. Hi. The only deaf person that I know that grow the way that I did. I'm not seeing it on YouTube, so let's do that," and here we are.

James: Now, as a blind user on YouTube, I can share the experiences vary based on the creator and their process for making their content descriptive.

Most of the time, you're probably not going to have a fully accessible watching experience on YouTube, because fundamentally, YouTube doesn't natively support a second audio track in their player.

Technically, they do. It's in beta, but the only accounts that have access are very few selected ones, and specifically, brands. Ubisoft is one example there, a game developer that started audio describing some of their game trailers, which is cool, but that happened many months ago and still no word on it rolling out to any other channels.

One thing I would love to do is some of the documentary films that I've done are professionally audio-described, but that doesn't live on YouTube for two reasons. One, I'm waiting for that extra audio track to become available.

Two, if I upload a duplicate of the video, which is different audio, it's going to hurt the original video with discoverability in search results because it considers it a spam, that I'm uploading the same video twice.

That is one strategic thing I have to be aware of. I always have to upload it elsewhere, link to it in the description. That's how that typically had worked in the past.

YouTube as well does offer the ability to listen to videos and lock your phone, but it's behind a paywall. It's with YouTube Premium service. If I want to listen to videos, which I will do a lot, typically, I have to go about...I have to pay $10 a month to have that feature, to just listen and not waste my battery life on my phone, which is...

It's not funny, because people on desktop, all the time, when I'm on desktop, I could close out the tab or switch to a different tab, continue to do whatever I'm doing, and listen to a video. It's a strange feature to hide behind a paywall.

Rikki: Almost everything accessibility-wise is behind a paywall. You want captions on Zoom? Behind a paywall. It's so annoying.

James: I don't think they thought of it as being an accessibility feature, but they probably should, because it's giving me the same access I would on desktop on mobile. This is strange. Just because it's a different platform, they decide there is a way to monetize a feature.

Beyond that, though, there's certain genres of videos that I do watching. I would say unboxing tech videos typically can be described, unless it's real cinematic and they don't want to commentate on what's happening.

Those sound-focused videos are pretty cool, but when it comes to people vlogging outdoors or traveling or hiking, it's cool to listen to all the noise, birds, the sounds of nature. I'm a big fan of that as well. In general, one nice thing is with the transcripts going back to the closed captions.

People who are deaf-blind are able to bring up a transcript and have a screen reader, whether it's JAWS, or VoiceOver, or Narrator on Windows, or TalkBack on Android, you can pop up the screen reader. If you have a Braille display, it will basically transcribe everything on the transcript to Braille, which is a neat feature.

Beyond that, it's great that YouTube has customizable fonts and colors with their closed captions, because if you are low vision, you can follow along with it. You can set the font up to 400 times the size, and I've done that before, because I have real severe ADHD. That with low vision, reading isn't my skill set.

What I can do at least, though, is I can follow along at the very least, when I have a visual reference of what's being said, especially, if depending on who I'm watching, it might be a little harder to understand, or I'm watching a different language video.

That's a great thing about YouTube, that it's accessible globally, and I can watch creators from different parts of the world. Even if I'm not a native speaker of that language, if there's captions, I can follow along with it to some extent. It's pretty cool.

Rikki: I started to add it. Before, when I was starting doing ASL videos, I only did caption, but then I looked at the transcript separately. I know it opens up on YouTube, but I also do Google Docs because it's a little bit easier because the transcripts on the side of YouTube can be a little bit wonky, at least from what I've experienced.

Then eventually, I started doing voiceover, which is complicated for me as [laughs] a deaf person, especially because if I would have a...D-PAN has our ASL caption business. They also have a voiceover business. I think for them, they could just go through it smoothly. For me, I have to do it by reading the captions. It's like this weird pause in-between sentences.

It's me trying to be accessible to my blind friends. That's me doing more work than YouTubers are doing. [laughs] I'm just like, "If we can do a lot of this, man..."

Annie: Yes. Oh, my God. Those are two really excellent points. Let me jot that down about [laughs] the abled creators versus disabled creators. I was really surprised to hear just now about how on YouTube you cannot close the phone and have it still playing. I've never attempted that. That's why I don't know.

I think there should be a lot more noise about how that is an accessibility feature and should not be behind a paywall. Yes, and...sorry.

James: I did tweet about it recently. It did pick up some traction. A lot of able allies or just followers of mine were like, "Yeah. You have a valid point there. That should not be behind a paywall." I think it did bring to light a little bit I should probably resurface and bring that up again.

Annie: Hopefully, a petition soon because it does need to be brought to their attention. I'm surprised in a very bad [laughs] way that we continue to not make any real uproar when a video platform opens up, premiers, publishes, and they don't have accessibility ingrained already. We just had this issue with TikTok and are still trying to figure that one out.

They are a video platform, just video. They have been running four years without any kind of captions. Fortunately, since there's a certain Generation Z focused on that app, they are really great advocates in certain respects. We can't generalize the entire generation, of course, but there's quite a few really excellent groups of activists in there.

So many of those creators were creating manually captions on their videos, which I thought was really excellent. They would literally type out what they said and put it as an open caption on the screen for their TikTok. That was really excellent to see, but it was still really appalling that TikTok hadn't created a captioning. This should not happen anymore. We are 30 years past ADA.

You cannot [laughs] continue to produce video platforms without thinking of accessibility at its very core at the very beginning instead of having it as an afterthought years after the program -- YouTube, TikTok, etc. -- comes out and Instagram. I'm looking at y'all, too. [laughs]

If you're trying to make a video platform, there needs to be a way to integrate captions that are not auto captions into the videos as well as not just captions but subtitles in different languages. People would take the captions that were on the video, the English captions, and then translate them and put subtitles on the video.

It allowed not just for creators who maybe either didn't have the money, time, ability to create their own captions for their videos for other people, for community contributions. It's literally what it was called -- community contributions, community support -- to help create those captions and to even make things greater to translate them into other languages.

It was last year. YouTube said, "You know what? Never mind. Take that out and not replace it. Nobody's 'using it.' We don't feel like it needs to take up space on the platform." There was not really much [laughs] we could do about it. They just took it away. [laughs]

Rikki: You need to keep this thing because deaf creators can use this, especially if everybody's like, "Why aren't these deaf creators not captioning their ASL videos, da-da-da?" "Oh, first of all, there can be that language barrier because ASL and English are two different languages." I was just telling them, "You can't take this out. We've had so many captions."

We have so many more caption titles because of this. People that I never watched before are finally getting people to caption. These other creators that I'm having a meeting with are not really getting any use out of it. Also, the people are like, "They're just not using it anyways because YouTube never really promoted it to begin with."

Also, the UI is terrible. It's inaccessible. It's hard to use. Also, a lot of people would do it on their phones, but they don't have it supported for phones. There's a whole market there that people are able to use. It's just really frustrating.

Annie: That's two things right there where YouTube really failed as a company. They failed as a company to let users know and to amplify the fact that there were elements in their website that allowed for you to make your content accessible. They really failed at getting in everyone's inbox and in everyone's face about the importance of accessibility on the platform.

Then we also have activists like James and Rikki, who were very vocal about the inaccessibility of YouTube. Then it comes to the problem with the segregation of the website where abled and disabled creators are not really integrated in that way. Whenever advocacy happens, it often feels like an echo chamber.

It feels just like the disabled community is willing to support one another and make things accessible for one another. That was a point that I wanted to circle back to with what Rikki said, which is how abled creators...and I'll use it versatilely. We can use "abled," "non-disabled," whichever term for short.

Abled creators would not take the time to make their content accessible. Even if they did come across the advocacy that either one of us have done, then there's just a matter of "We don't have time" or "We can pretend that we didn't see that" [laughs] "and can continue to do what is easier for us, which is not to make the content accessible." That's something that happens a lot.

Disability's not just one thing, right? As we're seeing in this very podcast episode, we have three different and similar-in-some-ways disabilities. There's different accessibility needs for different disabled people. It's disabled creators that are attempting to make their content as accessible as possible for other members of the community.

Meanwhile, abled creators are not always on the same boat, not always excited about or feel responsible for creating accessible content so that everybody that is online has access to it.

Keith: That's all a good reason to keep the conversation going about accessibility and repeatedly bringing it up. Hopefully, every platform it's on, someone hears it, and at least another mind has changed.

Let's talk a little bit about the online or virtual disability community. What is that like? How do you all lean on each other for support? Do you get to connect with each other, spend time with each other? That sort of thing.

James: YouTube does this great thing called the Accessibility Summit one time. It allowed [laughs] us to all connect once that they said would be an annual thing. It happens once four years ago, five years ago. [laughs]

Keith: It sounds like a metaphor for the whole accessibility thing.

James: Oh, yeah. One time and we forget all about it.

Rikki: Then all the spaces shut down. [laughs] Damn it.

James: All YouTube's facility for creators, they've gone the virtual route now, like their workshops and stuff. For me in general, especially within the creator community, I try to be approachable. I try to be welcoming. My messages are open for other creators.

I do run into the issue of people overstep boundaries all the time when you're a disabled creator. It's no ill will. It's like parents all the time, I'm suddenly your vision therapist. I can't be that. I don't have the time nor energy. I get [inaudible 18:42] in my messages and emails all the time.

That's not going to bring in any revenue for me to continue what I'm doing. I can't commit to these things all the time, but I always try to make time for other creators.

I am also involved with other spaces outside of just the central disabled community within tech and then creator economy-related channels and in-content creators. Trying to balance that out. Rikki and I are meeting up next week to shoot some content. I'm going to explore parts of North Carolina, which is really cool. I've never really been able to do that before. I'm very excited for that.

There's occasional times where we can meet up. Annie has been to California where I lived the last five years, which is cool for VidCon and other events. Those are always fun times to get together.

Rikki: It's funny how James and I met originally. He found me on social media years ago. It was 2015, 2016, something like that. Mostly, I'm sure I was looking for technology. He works at Apple. I was looking for a map-up. Yay. Then it just went off from there. We've been friends for so long. Then probably Annie I met around the same time.

Honestly, I don't even remember how I met most of all of our disabled friends, specifically. If you all just show up, and that was it. When things go wonky, especially with VidCon or Playlist Live where we would have these disability-specific panels or a workshop, obviously something would go wrong during each and every one of them.

Whether it was captions didn't show up [laughs] or interpreters didn't show up, we would have getting-up-on-stage issues. Then we would all just vent to each other about that or even if it comes to content and not knowing how to do something.

Obviously, like I said, I have issues with audio things. I'd just be like, "Hey, James. Help me." Basically, James is my ears. I'm his eyes. It's like this nice little power duo that works out, especially.

James: I think it's one of those things, too, where we just support each other's content as well. I try to platform other creators beyond myself. I still fall under what I think could be relevant or appealing to my following based on this. Tech-related, but it has nothing to do with vision tech. I don't know.

Cool accessibility features for those with a limited dexterity or who may be hard of hearing and sharing those cool innovations. It's one of those things where I'm a true believer and an advocate for the idea that accessibility can benefit all of us in universal design.

That, I think, goes through into my videos -- the mindset of, "Here's how I use this feature, but there's all these other ways that you could be using this in real-world use. Even if you have majority of your sight, there's other benefits to it." That's another way that we just try to connect through supporting each other's work, commenting, sharing.

Even just something I'm always trying to do -- if there's an opportunity that comes my way, but I don't think it's right for me. If I don't think I'm the right person to do that, I try to name-drop others in those emails or in those rooms. In one project I was working on they were asking me a lot about deaf accessibility.

I'm like, "I can tell you what I know as a person who does filmmaking and what I look for as a creator who tries to make my captions and everything accessible, but here's Rikki Poynter. Here's how to contact her. Fly her out. [laughs] Get her involved with this thing." Then COVID hits, of course. There goes the pay job because [laughs] it was literally that week.

Those are ways that we support and lean on one another professionally.

Annie: I think the different lenses and different perspectives are really important. Especially, if someone's only hiring one person to discuss a certain topic, then you want to give them as specific and as broad of a lens as possible. It's important to seek out intersectional creators as well. There is a specific word for it. I want to say that it's intercommunity accessibility.

It's intracommunity or intercommunity accessibility. That is something that I mentioned earlier on that is important to a lot of people who care about other people, a lot of disabled people who care about other disabled people, and not just themselves.

I will speak for us when I say it's important to us to try and do as little harm as possible. It's people who have experienced how harmful lack of accessibility is and how painful it feels to have that. There's so many elements to accessibility. There's the human rights aspect.

There's the emotional aspect of how painful it is to be excluded from something because of your disability, the pain of discrimination. Earlier, Rikki was like, "I don't even remember when we met." I wanted to say, existing as a disabled person in this society is traumatizing. We're not going to have the best memories.

It has an impact on the brain. It is a traumatic experience to exist in oppression every day, especially when you're working online. That oppression, you can't escape it from just being at home. It's literally in your comments section. It's in your DMs. That's tough.

To circle and focus back on the question that you asked which was about community, that intercommunity accessibility creation is vital and a huge part of why I'm so grateful for disability community. I want to make an honest observation and say that it's just like any other community in the sense that there are beautiful, communal, supportive sides to it.

There's also a more vicious and competitive, conflict, problematic side to it as well. That's not to say anything about any kind of hierarchy or anything, but just that there's harmful and toxic people in every community.

I want to mention that, because there's a weird assumption about disabled people. If you're disabled, then you're innocent, pure, and so on and so forth. Literally, this community is just like any other. There's going to be diversity of human beings. There's going to be people who suck in it. There's going to be people who rock in it.

I want to cap that all by saying that I'm grateful to be, for the most part and if they're toxic, I release, surrounded by people who rock. If it wasn't for disability community online, I probably would have never gotten diagnosed. My diagnosis is Ehlers-Danlos syndrome which is a difficult diagnosis to get so far. Hopefully, that's changing.

It's thanks to the mentorship, the communication, and the support that happens online, that something like that can happen.

Keith: A couple of you alluded to what I want to bring up in the next question. You all three share about vulnerable topics and experiences online. What is it like for each of you, that combination of pleasure and pain of storytelling? How do you take care of yourself in this work?

Rikki: Last week, I went to LA for I could use maybe season two premiere, "A Quiet Place" episode "Alive," next Wednesday, just tell you on that. [laughs] For me, like I said, I have chronic pain at the cheek. Usually, I can get by. If I'm on my own, like I'm going to Target or whatever, if I'm on my own time, I don't have to worry about rushing, even if it is a long area.

Like James said, we're going to go on a road trip next week. We'll be doing our own thing. Honestly, we know each other so we could take walking breaks or whatever that's needed. When it comes to things like airports, you are on a schedule, you gotta hurry up.

I was getting a wheelchair from Charlotte to my connection, the Burbank da-da-da. I had an issue flying from Burbank. I needed to make my connection. We were waiting 20 minutes for a wheelchair. A Delta employee comes over, a Delta employee tags, uniform, and all.

They knew we were waiting for a wheelchair 20 minutes. I started to walk up to [inaudible 27:16] . A flight attendant was like, "This is your person that you need to take to the connection that's leaving in 20 minutes." It's a big airport.

They saw me get ready to sit. Then, they just walked away with the wheelchair, but without me in it, or even without my bag. I was carrying it on my shoulder because it's very heavy. Now, if they had offered to let me put my bag in the chair, then I could have walked up because I don't have all that weight on me.

They just walked off without me. I was like, "What the heck?" I had to struggle my way up the hallway. I made a video about it. A couple of people are very dismissive about it. One was like, "It sounds like an exaggerated/made-up story from a chronic complainer," who was subscribed to me for a while, and I was like, "I think you need to take your subscription and go somewhere else," or, "Why are you here?"

Another one was like, "You don't need a wheelchair. You're fine. It's not like you got hit by a car." This person was a four-year subscriber of mine, and I was like, "Are you serious right now? Why are you telling me that?"

Anyway, they deleted their comment the next morning. Stuff like that, or when I talk about anything, and when it comes to being deaf as an accessibility issue, people get upset about that.

Usually, on my channel, even if it is not frequent, at least I can control that, but if I'm doing -- I'm right here -- if I'm doing a collab with somebody else, especially bigger YouTubers like Tommy Edison, who was another blind man. He has a huge channel. We've done collaborations.

Sometimes, I was speaking to him, and people are like, "Oh, my God. She's not deaf. She's talking, da-da-da." If I'm on a abled-creators channel like Life Knock, and I did a collaboration with them, people will be saying, "More stuff," and it sucks.

Coming as someone who had grown up with child abuse and stuff for a very long time, and even now it's still dripping into my life, it sucks to be vulnerable. [laughs] "Yeah, great. What else is there? Another person who doesn't believe a disabled person because [laughs] everything we say must be exaggerated."

Just because it's not happening to you, doesn't mean it's not [laughs] happening. Just because you don't see it, doesn't mean that it's not happening.

James: You brought up some good points there, especially, around the airports are a good example of inconsistent accessibility. As a blind person, we get wheelchairs offered all the time. Sometimes, forced upon, but I don't mind them. Sometimes, I will take it after a long flight from Europe, for example.

I want to sit. I want to lay down. It's 2:00 am, take me away, but in most scenarios, and this is more to do with my own chronic pain I face, which I don't talk about a whole lot, but I have sciatica. That specifically for me, in my lower back, requires me to either sit or stand or switch after 30 minutes.

If I'm sitting there in a wheelchair and being forced upon it, it's going to take more for me and cause more body fatigue and pain, especially after I sat in a car to get to the airport for the last 45 minutes or so. That's where I'm like, "No, I need to stand and walk. I need you to guide me. Let's do this together."

"Because you're not trained to guide, that's fine. I will tell you. I need to hold elbow or a shoulder, and I have my cane out on the other side for my own spatial awareness." It's one of those scenarios where sometimes, people aren't fully trained on how to accommodate. That's OK. It's about treating us like humans and asking for permission rather than...

Annie: The specifics of each different disability is so hard like you're talking about. That's a very specific thing. I can only stand or sit for 30 minutes at a time, and I wish more people would ask that instead of making assumptions that disability is so binary. It's like on, off, etc., or only one or the other.

If you're blind, you cannot possibly have any other disabilities. Me, with EDS, which EDS is a diagnosis that means my collagen sucks, my connective tissue sucks. That's all that means, then I have a list, a bullet point list of other disabilities that I have, and the diversity within each one.

God, I wish people would ask, "What are your specific limitations? What kind of support do you need? What kind of help do you need?" because I have a similar thing where I can stand up and do a lot of things within a 60-second parameter that appear very able-bodied.

I can maybe dance. I can maybe jump. I don't know. I don't want to risk jumping usually or risk running, but I feel like if I was in a near-death situation with adrenaline, maybe I could pull it off, but certain efforts are risky.

See how specific these disabilities get. I wish people would ask specifics instead of making accusations of, "You're this, so you can't be that. I saw you do this, so you can obviously do that," and whatever other thing they want to assume about you.

Keith: The flip side to the previous question, what are some of the advantages related to your disability and other identities that you've discovered along the way when working on YouTube or creating content in general?

James: I was going to say in general, front row at concerts, but in terms of creating content, we're all coming from different perspectives that are quite unique.

YouTube being what it is. It's a platform that it's the leader in online video content creation, but it also democratizes content creation and giving us all a space where we can put ourselves out there.

Whether or not we get discovered, or whatever we build these communities, it's a bit on the work, and [inaudible 32:53] we're learning a little bit of the strategies behind it, as well as a little bit of luck. [laughs] I think it comes down to it, too.

We have some advantages where we can share these different perspectives and help bring awareness, and try and create this more inclusive world that I don't think we've seen a movement like this ever before for the disabled community.

I look back at the 1980s when Louis Braille invented Braille, and he did it as a way to communicate and not feel controlled over by the sighted teachers and the faculty at the school for the blind. This is in Paris by the way.

He created Braille so that he could write and communicate with other blind students. They were learning it, but then they couldn't control this new form of writing, so they were burning all the Braille materials, the faculty and the sighted people. Braille wasn't even adopted until after Louis Braille's death in the late 1800s.

That took a whole lifetime for something like that to help push independence, and he's on the record of quoting so many progressive, especially for the time, progressive mindsets around independence with all people who are disabled.

Nowadays, we have this ability to connect like never before on a global level, and share and communicate with people in other parts of the world where it is more accessible, architecturally speaking, than it is here back in my home.

We can be like, "Look what they got. Let's lobby for this in our town, or bring this up to Congress," or vice versa. It's one of those things where we can exchange ideas and the way that we are perceived, and take control and take back our representation going back into the media.

By us being able to broadcast ourselves, we can raise awareness of these issues. I'm not satisfied with how blind people have been portrayed in the movies and in TVs. I want to change that.

I've been trying to progressively do that in my career, and I've had some cool opportunities to push for better representation for my community on screen, and get more visually-impaired actors behind or in front of the camera, and also working behind the scenes.

YouTube has helped to change the way that our community is seen, but then also involved with everything from accessibility to inclusivity.

Annie: I find that a hard question to try to figure out the positives of my condition, because most of it is bad. [laughs]

Rikki: Yeah.

Annie: Anything that I can come up with is problematic. To say things like, "I can do a party trick," when the truth is doing things with our hypermobility is potentially harmful in the long run.

Among my disabilities, I'm also autistic. I'm very grateful for my autistic brain, and how existing as an autistic person in this society and how I communicate, whether that is from the autism itself or the trauma of the ableism that I experienced as a young, undiagnosed autistic person, all eventually led up to me communicating the way that I do today.

I don't know. I'm very grateful for that ability to be able to communicate myself in the way that I do. I'm grateful to exist in this body and with this condition that I have, because it is a very specific lens that I'm able to communicate to other people and advocate for in that way. As James was saying, the advocacy that this has allowed me to do really feels very fulfilling.

I say that. Again, as a very honest person, I want to show the other side of that coin as well. I feel very fulfilled by my work as an advocate and fulfilled by the work that I do as a communicator and as a storyteller. Storytelling is a huge part of who I am as a person. It's part of my nature. It's something that I've done for the majority of my life, but it does take its toll.

That goes back to the vulnerability online aspect in your earlier question. It recently, definitely in the past year, has had a tremendous impact on my mental health and made me examine my relationship with privacy, my relationship with social media, and my relationship with parasocial relationships from social media as well.

This is something I've been discussing periodically on social media, on other podcasts, and now this one is included as well, to examine those things, examine my mental health. If I feel that I need to change how I do my work and change how much information I give about myself to the public, to the Internet, then I have to do it as best for me.

We gotta follow that philosophy of you can't serve from an empty comp. I said comp, but I meant in cancer, from an empty cup. You have to make sure that you have your back first before you have everyone else's back. What is it? The airplane rule. The airplane rule is make sure that you have your mask on before you put a mask on somebody else.

Just to circle all that off, just wanted to answer two questions in one go, which is the vulnerability aspect. I am very grateful for that part of myself, for how I communicate and for the ability to be vulnerable online so that we can discuss these topics and hopefully change things.

Keith: My next question was going to be related to why YouTube, compared to other platforms, what's better and worse. I feel like we've already talked a lot about the problems with YouTube. Then James, you mentioned the positives of it. Does anyone else have any comments regarding why YouTube...?

Rikki: I think for me, it's just because it was the most popular platform at the time. It was like, "All right, let's use that." Then it just continued on from there. It's only grown more and more.

Annie: YouTube has longevity. It's connected to Google. This is an observation, so correct me if I'm wrong. A lot of the work that the three of us have done is with search engine in mind. When people will search certain questions regarding our disabilities, we're like, "OK, if you're going to search that question, I hope that this video pops up." There, you have the answer.

It has the longevity in that way. Again, I'm repeating myself, I know, but connected to Google. Google is the most popular search engine right now. That way, it feels adding something into disability history. It feels like adding things into the Wikipedia, the knowledge textbook of disability by putting our narratives on there.

Keith: That's an interesting way of thinking about it. I had never thought of it that way, but that makes a lot of sense. You've also talked a little bit about some of the joys that you get from this. What brings you the most joy from creating this content and getting it out there to people?

Annie: I love when folks share with me that they're working on internalized ableism. My community, firstly, is very important to me. I want there to be questions about internalized ableism, about confidence, about disability pride.

I want people to question themselves about their accessibility needs and what kind of devices or tools that they may need to move through this world with more ease. I don't want to say ease. I don't want to say perk. I don't want to use any of those extra words. I want to make it clear that accessibility needs and getting those needs met is about equality.

It's about equity and about making sure that you stay alongside the rest of the community that's not disabled.

Folks who were questioning their use of a mobility aid and worried about their confidence level, or wondering if they're "disabled enough" for that mobility aid. Then through watching or reading any of my work, they've decided that they are entitled, and that's something that they are allowed to get for themselves. That makes me happy.

Rikki: For me, growing up as a mainstream deaf person, which is very like in limbo. I don't fit in with the hearing world. I didn't fit with the deaf world. In a way, sometimes, I feel like I still don't, but it got me to meet other deaf people eventually to find that deaf identity and learning sign language, things like that. That was nice.

Even though I'm not fluent in ASL by any means, still, if I'm going to go hang out with new deaf people, I still feel good with them and a little bit more comfortable. On the other side of that, people, they were also looking for mainstream deaf people to find.

When I was first getting on YouTube, most of the deaf people I would find were those that grew up in the culture, and no sign language, da-da-da. We had that connection. "OK, they're deaf. Yay," but it still wasn't the same because I didn't know any ASL that sounds like the alphabet.

There are people who would come into my comments and be like, "Hey, I grew up with hearing parents. One hearing parent, another oral parent," or whatever. It's nice to see you to talk about this and that because somebody can relate to my struggle. Then you got me learning ASL, or whatever.

Even if I'm talking about chronic pain and fatigue, because when that start creeping up, I could talk to Annie about it, or talk to some other friend that could relate, because I'm trying to figure out what's the best way to deal with the situation, or whatever.

A long time ago, an old friend was telling me about how they saw some...I think it's their little girl or somebody. Some random little girl in the airport pulled up one of my videos, [laughs] and they're like, "Hey, no laughing," or whatever. "Have a good time."

I was like, "Oh, so cute." Then people tell me, "Hey, I started captioning my videos," and I'm like, "Yay, that's awesome." It's nice to see that.

James: For me, one of the coolest things I got to do earlier this year was connect with the...People connect all the time through comments, and then share their takeaway from the video and how it impacted them positively. Those are always so meaningful.

One person who I connected with, his name is Timmy, and this was in part thanks to the YouTube Channel, "Special Books by Special Kids." Timmy is blind, and he was abandoned by his parents because he was blind and [inaudible 43:30] . He was found on the side of the highway and adopted.

Timmy is about 12, 13 now, and he had been struggling with accepting the circumstances, the blindness. I know around that age was when I hit my darkest point in life, and there's always dark days. There's always those tough days, but a lot of us in our journey are going to have those periods that are longer than a day, than a week.

It was meaningful being able to talk to Timmy. It was through Zoom just like this, and I encourage him and tell him things he wanted to do. He wants to travel and experience other towns and cities, and be able to take a train independently.

Being able to reassure him that that's something that it's going to be more than possible, especially going into your later teens, with orientation, mobility, or something. I don't even know how to take a bus properly. I'm getting trained on that right now, which is cool.

The states, the federal services offer orientation, mobility training for visually-impaired and blind people. We have someone who teaches us to go out, and how to take a train, how to go to the airport, how to use our cane, and how to find those routes and then paths.

I'm going through it right now. As I'm in the process of getting a guide dog, I need to be up to date with all those skills. Being able to reassure him that that's something you're always going to be working on, but it's going to be more than possible, and he's not going to need to have his adoptive parents with him 24/7.

The world can be taken on independently, but it's also totally OK to ask for help. Connecting with Timmy was one of the coolest things, and the videos on YouTube, again, Special Books by Special Kids. It's a great channel. It's trying to represent disability in a very approachable but family-friendly way. Kids who are young can see disability on screen.

Keith: Let's close by talking about Disability Pride. It's July and the Disability Pride Month. Also, the anniversary of the Americans with Disabilities Act or ADA is coming up on the 26th of this month. Tell me your thoughts on Disability Pride, and how the ADA has impacted you.

James: For me, being proud with who I am, my progress, my journey with my disability. That's what I reflect on and think about when I hear about Disability Pride Month. I'm sure it's been celebrated for a while, and the ADA and all that, of course. The concept of disability pride, I've only heard about in the last year.

That aside, though, going back to the reflection, it has helped me to look back at my journey with my disability, where I was a kid who hated opening my eyes and knowing how I see the world. I can't see the world like everyone else. That my eyes have to visually look different when I'm trying to give someone eye contact.

Is that what they're focused on, because they can see my eyes wobbling and moving? It's a constant thing where I was very insecure about my visual impairment growing up. It took me to some pretty dark places. I won't touch on that.

The progress I've made coming from that to accepting and believing that there's a reason. I had an experimental surgery that was meant to improve my visual impairment and to improve my vision. It actually did for about two to three years. Two and a half, really. Then overnight, all the progress went away.

My brother got the same surgery for his eyes. To this day, he's still at the mark where he could technically get a driver's license. Doesn't feel totally comfortable to do so, but he could. Never been there. I will never be able to get there. In fact, I've had more vision loss, actually, recently.

It's one of those things where I'm completely content today in my body, in my eyes. It's about taking charge. I never was fully offered all the accommodations I should have been growing up. I had to learn those. Learning how to use a white cane. Learning that text to speech is a relatively accessible option for me, and that I can't read.

Accepting those things and my circumstances. Knowing how to accommodate myself, as well as being able to ask those to help me in those scenarios that I needed. That's where I'm prideful of where I am.

That I'm able to share those experiences with other people online who maybe are going to go through the same thing, whether it's a different disability but similar concepts and struggles, or they're visually impaired, and they're trying to figure out how do I ask for this accommodation because what they're offering me in school right now is not working. I just want to pass, get through, go to college, and pursue my passion and dreams.

If I can have the smallest step in helping to make that positive impact, and show where my mistakes are or where the mistakes were with where I was failed, that's what it means to me, is reflecting on that whole journey.

Annie: Me having my health decline and being more loud on the Internet about disability adequacy came around the same time. Learning disability history and learning that the ADA was signed in 1990 July 26, that immediately did become something to celebrate to me, whether anybody else felt that way or not.

I did not know that it was something that the community at large is celebrating. When I was learning disability history, I was like, "This is freaking important. It should be acknowledged and it should be a holiday."

Let's have fun with a little astrology for a second. I'm a Leo. I have one birthday. For me, it's the birthday month. I expand something that I feel like is worth celebrating into as long as I can. [laughs] That's a bit how I feel about July. I honestly needed this, needed the fact that so much of the community is on board with disability pride.

Again, there's a dialogue happening that I didn't even know was happening. Fine, if you want to call it something else, there can be a dialogue about that. I think that we have a month to honor disability and to celebrate disability is very important for a number of reasons.

I needed this. July 26, while it's an amazing day to celebrate in terms of disability rights, also has been a very traumatic day for myself that I relive over and over every year.

The event that I'm referring to is the massacre in Japan, where a man murdered about I believe 19 people in a disabled community home because they were disabled, and had very eugenics beliefs that mass murder...about how if he murdered several communities of disabled people, that that would benefit the economy, etc.

I probably should have said trigger warning before I started telling that story. That was the same year that the Pulse massacre happened. As a queer disabled person, it hit me. It triggered me and depressed me.

The difference I saw nationwide and in global support after the two massacres happened, where when the Pulse massacre happened, there was plenty of solidarity among online communities, businesses, news. Newscasts that were like, "Listen, LGBT community, we support you." Affirming the LGBT community's existence.

That was very needed. When a massacre like that happens, it triggers you into this fear response of, "That could be me at any moment." That's definitely how I felt after Pulse. Pulse is very close to me. I used to go there a lot. That whole experience was very scary.

When that night happened, I was scared that my friends might have been there. Waiting to hear names and waiting for texts back. Horrifying. Then when this massacre happened against disabled people, it was only disabled people talking about it online. That made me feel like, "Yeah, nobody cares. Nobody's listening."

It still makes me emotional to this day. That reminder of a massacre can happen and a hate crime can happen to disabled people and non-disabled people or the masses don't respond to it. Either don't know about it, which is one thing. Don't respond to it. Don't care.

That's something that literally every July since then has been something that's been a cloud over my head. That's something that I also, as a content creator, and as an activist online, I'm reminded of constantly.

That all the work that's being done, there's still so many people who are very actively against disability rights, very actively against disabled people existing in the first place. Actively against disabled people having pride in themselves or celebrating themselves as disabled people.

It is very affirming to me to have a dedication of a month celebrating us, honoring us. Hopefully using that month to get some bills passed. That was something I did this week, which was write up some very short scripts and some ways for people to support bills towards disability rights, the SSI Restoration Act, Air Carrier Access Act amendment, as well as a move to...

It's a complicated name, but to create equal pay for disabled workers and not segregate disabled workers from non-disabled workers. It's a very busy month. [laughs] All this is coming at me at the beginning of July and I'm like, "Ooh, we've got to make moves. We've got to go."

I'm glad that it's here. I'm glad that maybe that's just the little push that's needed for people to start listening. I want a light shining on our community, especially in these areas in politics, where we need it most towards our disabled rights.

As I mentioned earlier on, I think that pride in oneself as a disabled person, confidence in oneself as a disabled person, and battling internalized ableism because we all have ableism that's part of us. Ableism has been taught to us since we were very little. Being anti-ableist takes effort, takes work, takes learning and unlearning things.

It is so vital. It is so important to me that people take the time to examine their beliefs and examine their actions to become anti-ableists.

Rikki: Finding a disability community and learning more about ADA stuff, now I can send emails. I'd be like, "Yeah. I'm going to need it because the playlist is a little bit more complicated than VidCon." I don't know what it is. When I would have a workshop or put a panel on, I'd be like, "Hey. I need an interpreter or this and that."

Sometimes they'd be like, "Are you sure you need that?" I'm like, "Yes, I'm sure. Yes, you have to provide it because you are a public event. It says right here, 'Public events, you provide the thing.'" Then they'd be like, "Oh, OK. Fine." I'm like, "Yeah. Right here. Fine, fine." There's that.

I've always said that being deaf in itself isn't a horrible thing. It's just a lack of accessibility or a lack of having other people like you to be friends with, to have conversations with, anything like that. Having a disability five months or whatever heck anybody wants to call it now, it's just nice to have. You see it on Twitter even still.

People are like, "Oh, my God. I never want to be disabled." I would answer, "Bad thing, all I do it by myself here." They say, "Oh, my God. It's exhausting." It's not to say that we're never depressed about being disabled in one way or another just because it's not all like sunshine and roses. We're going to have our moments.

At least for me, mostly when I'm by myself, some days I'm just like over it. With the Disability Pride thing, it's nice to have people come together and be like, "I'm cool with this, at least for the most part." Then it's, "OK, cool. Give me that little positivity. It's very helpful right now, especially when I'm sad, so bring it."

Though it would be nice if more non-disabled people hopped in every once in a while in conversation because, again, it's like that echo chamber and, "We don't need only disabled people be in a cage." Most of us have [inaudible 56:33] the nation. I'm trying to go for it. When all the abled people listen to other abled people only, but not us.

[laughter]

Annie: That tends to happen. It was DeBlasio that said it's Disability Pride Month. I think that's what happened. I want to hope that, with a civil acknowledgement, that there is a Disability Pride Month honoring disability that it does become a more -- What's the word I'm looking for? [laughs] -- a bridge-crossing, for lack of a better term, and that people start to shine a light.

Gosh. Look at how...

[crosstalk]

Rikki: ...or it's not going to be the end of the world if you become disabled. Obviously, if someone's been abled all their life, I'm not going to be like, "Wow. How dare you hate this right now? How dare you hate being deaf right now?"

Annie: Disability Pride has room for those kind of complications and nuances. I think that any kind of jarring change in one's life is going to have a grieving process. It's going to have some adapting periods. Disability is the same way. My disability pride did not come without moments of...and to this moment because I have chronic illness.

There's a lot of painful and difficult aspects about the disabilities that I experienced. It's not always, "I love my disability," or "I'm proud of my disability." I'll take that back. Pride is a consistency in it. I'm proud to be a disabled person. I'm proud to be part of disabled community.

There's going to be people who have that pride in self and community and still have complex feelings about their disabilities, still have complex feelings about their bodies. Still have complex feelings about existing in an ableist society that is not entirely accessible, despite the fact that we have ADA in this country, despite the fact that it is illegal [laughs] to be inaccessible. We're still fighting it because people do illegal things all the time.

[laughter]

Annie: Despite the fact that we have laws against inaccessibility in this country, we are still fighting for rights and accessibility on a daily basis. As I mentioned before, that's something that is traumatizing. It impacts one's personhood. It impacts one's mental health. It impacts how we move through the world. It impacts the glass ceilings that we experience in business as YouTubers.

There's so much to process as human beings who are disabled. You can have all that. You can have grief. You can have insecurity. You can have your adapting period. Yes, I think that the more that people introduce disabled narratives into their lives by watching disabled YouTubers, by adding disabled creators to their feed. I wish it was in schools.

I wish that disabled culture and disabled history was something that was actively taught to students, actively taught in schools. That way, we would create that kind of a sentiment.

We would create an environment where children, and children become adults, so people of all ages, when they get...I don't want to say threatened, but confronted with the possibility that they might gain a disability in their life, that it is not the end of the world. There are ways for them to adapt instead of being completely fearful.

Then yes, I still want to amplify a moment of grief. It is hard to make those changes if you've experienced your life one way for a very long time and then have to abruptly change it. There's going to be grief that comes with that.

I hope that the existence of the disabled community, the resilience of the disabled community, and the fact that they're creating content that shows you, "Hey, I'm blind, and this is how I use a phone. Hey, I'm deaf, and this is how I make these events accessible for me," etc.

"Hey, I have horrible chronic pain and joints that want to dislocate at the site of any pressure," that you can use mobility aids, braces, and things that can help. Those are one of the great things about disability community, period. That disability community is here to support one another and to learn from one another.

Hopefully, again, just to round that all off, it's a big part of making anti-ableism work a part of the majorities' efforts instead of the minorities' efforts.

Keith: I think that's a great closing statement right there.

Rikki: Round of applause.

Keith: Yes, indeed.

Rikki: [laughs]

Keith: Thank you all, Rikki, Annie, and James. This has been great. I appreciate all your insight. Thanks again. We appreciate you being our guests.

Rikki: Of course.

Annie: Hey, thank you so much.

James: Thank you for the conversation.

Keith: Thanks again to my three guests, Annie Segarra, James Rath, and Rikki Poynter. Make sure to find them all on YouTube. Their channels are great. You'll be both informed and entertained. You can just search YouTube for their names to find their channels, but I'll also include links in the show notes.

Don't forget that very soon, you can find You First on YouTube as well. Search for Disability Rights Florida to find our channel or jump directly to it at YouTube.com/disabilityrightsfl. 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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