

## You First Podcast Episode 49: Who's Missing in Florida's New Youth Survey

**Keith Casebonne:** You're listening to "You First -- The Disability Rights Florida Podcast." In this episode, I talk with a panel of guests about Florida's withdrawal from the Youth Risk Behavior Survey and what that means for Florida's youth.

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**Keith:** Hey, everyone. I'm Keith.

**Maddie Crowley:** I'm Maddie. We're the hosts of You First. Today, Keith has a great panel of folks on to discuss the impact of Florida leaving the Youth Risk Behavior Survey.

This is a survey that is widely given to youth across the United States to assess things like mental health, teen dating violence, drugs, sexual activity, etc. Just used to see where trends lie in these different behaviors and activities, to then use that to create policies, different programs, and better the health and well-being of teens.

The survey has really far-reaching applicability, like I said, policy and programs. A lot of people use that data, including Florida in the past, but Florida no longer participates. Which leaves folks curious about what metrics will exist to track youth and teen safety trends. Instead, earlier last year, Florida created its own survey, FSYS, or the Florida Specific Youth Survey.

**Keith:** Yeah, that's right. To break down the timeline of all this, Florida's decisions, the old and new surveys, and the impact all this will have on Florida's use, I spoke with three guests. The first guest is our very own public policy analyst, Caitlyn Clibbon. You've probably heard her in previous episodes of the show.

Our second guest is Nadine Smith, who is the executive director of Equality Florida. Equality Florida is Florida's statewide civil rights organization, dedicated to securing full equality for Florida's lesbian, gay, bisexual, transgender, and queer, or LGBTQ, community.

My third panelist is Dr. Norin Dollard, who is the senior policy analyst and [inaudible 2:18] director at the Florida Policy Institute.

The Florida Policy Institute is an independent, non-partisan, and non-profit organizations dedicated to advancing policies and budgets that improve the economic mobility and quality of life for all Floridians.

**Maddie:** These three guests address the reality of Florida leaving the survey, and discuss their really deep concerns about the impact of withdrawing from the original YRBS survey and that impact that it's going to have on marginalized folks, including people with disabilities.

**Keith:** Yeah, certainly. We hope you enjoy the episode. Without further ado, here are Caitlyn, Nadine, and Norine. Hey, thanks so much for being our guests today. We really appreciate it. Let's just jump in with talking a little bit about Florida's withdrawal from the Youth Risk Behavior Survey.

Let's first just tell people what is the Youth Risk Behavior Survey, and what are the benefits that participate, share data with that.

**Norin Dollard:** Sure. I'm Norin Dollard with the Florida Policy Institute. Have been working on this issue since it first came to light a year ago, a little over. The Youth Risk Behavior Survey, or the YRBS, is a longitudinal survey. We've been doing it since 1991 here in Florida.

The purpose of the survey is to really get a good handle on the well-being of Florida's young people and is across multiple domains, talks about physical health, like how often do you breakfast? It talks about risk behaviors like, are you been in a car with somebody who's been texting? It talks about substance abuse and mental health risk factors as well.

It's been very important for shaping public health policy, for helping school districts design intervention and prevention efforts for their students. Folks use it in grant applications. They use it to bring grants to their communities for suicide prevention, for example. We use it in the state [inaudible 4:27] , or we used to, in order to draw down federal money.

It's pretty widely used. Probably a key feature of the YRBS is that it allows us to know who the important subgroups are in terms of race and ethnicity, as well as how young people identify themselves.

**Nadine Smith:** I'll jump in to say that the importance of this research is that it literally saves lives. It helps us track depression, suicidality, whether or not students are more likely to drop out of school, how much mental health support and other kinds of support young people have.

Many organizations that fund, foundations that fund, education and the well-being of young people count on it to track whether or not the tools that they're using are having the intended impact. For a number of years, we were able to look at the YRBS.

After the state passed anti-bullying policies and there was greater training for teachers and other educators and staff to intervene, we were able to see through this long-term, year-after-year research, that the things we were doing were improving outcomes.

Then as we began to see some of those resources stripped away from schools in these last couple of years and the tenor and tone directed certainly at the LGBTQ community, but also around removing books and the rhetoric that has become increasingly hostile and divisive, we began to see, in the last two years, those numbers decline.

For Florida to simply pull out of this completely has really been quite devastating because, as Cara James at Grantmakers In Health says, we can't fix what we don't measure.

The Youth Risk Behavior Survey is a critical part of measuring things so that we can address those very serious issues that impact the quality of life and sometimes the survival of young people who are dealing with so many more pressures and harms right now.

**Caitlyn Clibbon:** This is Caitlyn, I'll just add, on a more granular level, in addition to what Noreen and Nadine said, I've heard of pediatricians even who follow these survey results, and they'll say, "Oh, I'm seeing a real uptick in kids at a younger age using a certain substance," or something like that.

Then they decide to use that information to speak with parents and their patients and to counsel them on those things knowing that, in their particular community in their area, that it's a growing issue. It's big picture, and on a granular level, that this information is being used to help kids.

**Keith:** It sounds like the YRBS is a fantastic resource and can be used by so many disciplines to look at trends and things that are happening for a number of groups related to youth across the country, but Nadine, as you mentioned, Florida has decided to stop being a part of that. What does that mean? Why did Florida stop participating?

**Nadine:** Honestly, the reasoning behind it has not been explained in any clear way. The way that the YRBS is set up, for example, if you didn't want to ask a certain set of questions, the state could have said, "We won't ask this group of questions."

Unfortunately, I think it has become so politicized because this survey is done through the CDC. By all accounts, it appears that Florida just wanted leadership, wanted to thumb their nose at the CDC. This is in an environment where a student wearing masks and vaccines has become politicized instead of simply physical health.

One of the things that I think people in the current administration would say was, "We've replaced it with something else." What they've replaced it with, there's a reason that you do longitudinal studies that allow you to compare datasets one year after another to see where those changes are.

You can't simply replace with different questions framed differently, and you can't create a document as powerful, and potent, and essential as this in the manner that Florida intends to.

It is a real blow to have removed the ability to track youth mental health and behavioral health, and be able to compare it year to year and compare it to other states even to say, "You know what, they're doing better than us. We should go and look and see what they're doing that is producing better outcomes than we're getting here in Florida," or vice versa.

If Florida were doing better than another state, they could look at what we're doing, make comparisons that are logical, and compare apples to apples. That's how research allows you across time and across geography to continue to improve the climate for young people.

**Caitlyn:** I'll just add that the CDC paid the state to administer the surveys, so as far as the reason why they pulled out, it's not a matter of cost and it's not a matter of whether we're going to survey students or not.

We're still surveying students and the YRBS was administered alongside two other surveys that the state does. There were no problems with the schools being able to administer the survey, so it felt out of thin air when the state made that decision.

**Norin Dollard:** As far as we know, there were no complaints according to the statements made by then acting commissioner of education [inaudible 10:20] is an out survey. It's not compulsory. If the parent had some objection, they could have said, "OK, fine. My kid's not answering this."

It would have been the end of it. We're not aware of any, as Nadine said, there's no revealed reason why, explicit reason why, we've withdrawn.

**Keith:** Based on everything you just said, I can't really understand either why we would want to do this. What is Florida doing instead? Is there some alternative to the YRBS? Either that they're using or developing, or are we just not going to look into any of this anymore? We're just ignoring these groups.

**Norin:** This survey that was administered this spring and Caitlyn can talk more about it some of the development aspects, but the survey that was developed and administered this spring is I would not call it a replacement. It is a different survey.

It really, for the most part, assesses Florida's best standards that look at character and resilience and important things, but it is not a replacement for the YRBS in this. It does not address the various physical, substance abuse, mental health domains that the YRBS does.

In the instances where it asked questions that are along the lines of the former YRBS, the question for me, at least one question for me, is if it wasn't broke, why fix it? Those questions were fine. They were psychometrically tested to be reliable, valid indicators of those things, and then CDC paid for that testing and development.

As Nadine said, having changed the wording, we cannot compare where we are to where we were to understand what we need to do better or to show others what good interventions and options are.

**Caitlyn:** Let's be crystal clear. This administration has pulled Florida out of the YRBS for nothing but naked political reasons. It has nothing to do with making school safe. It has nothing to do with improving the survey. The YRBS was developed through a rigorous process, and it has evolved during its 30 years in existence in content and methodology.

It's changed and adapted to reflect changes in young people's behaviors, such as vaping. Vaping would have been on the first ones.

The information that it collects and the representative sample of public and private school students, that data has been a really comprehensive way to say especially now coming out of COVID, where alienation, isolation, depression, all of these things, and at a time of deep political divide in the country, where so many things are being talked about schools.

What can be taught, what books will be banned, and which books will be allowed, all of these conversations are happening in a swirl where students are seeking to find their way. There has never been a time when we've needed this tool more than we need it right now.

You compare a 30-year history of rigorous process and methodology compared to something they've slapped together in private to serve a political agenda, not the needs of young people. That's what we're dealing with in the State of Florida right now.

**Nadine:** I just want to add briefly that the state itself has used this data. The state uses data to talk about why kids needed to go back to school during COVID because of their mental health declines. The state has used this data to support its own mental health initiatives. It's valuable data.

**Norin:** Listen, the elephant in the room here is that this is a survey that along with all of the questions about bullying, about substance abuse, about suicidal ideation, about all of these issues, race, drug use, also surveyed who identifies as LGBTQ, who comes from families that are LGBTQ.

In an environment where books are being taken off the shelf no matter how benign where "And Tango Makes Three," the true story of two male penguins raising a penguin chick is labeled pornography and taken off the shelf.

We are dealing with a lot of irrational decisions that are made in the name of sending a message of hostility towards the LGBTQ community. That's whether it's young people or LGBTQ families.

The timing of the removal of the YRBS certainly indicates that this is part and parcel. The same campaign that led the Department of Education to pull down all anti-bullying resources that had anything to include how teachers can mitigate harm to LGBTQ young people.

I don't want to glance past that, but I also believe that this is a place where national and state foundations, organizations that serve young people, rely on this data, and now we'll be flying without a map, without ground control, in trying to navigate one of the most complicated and perilous times for young people in our state.

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**Andrew Garza:** Hello there, and welcome to "Disability After Dark," the podcast shining a bright light on disability stories. I'm your host, Disability Awareness consultant, Andrew Garza. This is a podcast where you sit down with your close disabled friends and talk about things in the disability experience that we never ever get to shine a light on.

That's why it's called Disability After Dark. Each week, we'll explore everything from disability to ableism to sexuality, and so much more, including things like disability grief, disability joy, and so many different conversation topics around the disabled experience.

We even have special bonus content like "Quarantine & Chill," a podcast within Disability After Dark, where we explore the effects of the ongoing pandemic or a "BUMP'N" podcast where we talk all about sex and disability and sex toys on the show.

Tune in wherever you get your podcast, and let's shine a red light on disability stories. Thanks, everybody. Bye.

**Narrator:** Dating with disability can be hard. I know that thing because [inaudible 17:20] for years to date [inaudible 17:23] with a disability. Having [inaudible 17:29], I encountered many people not even considering me as a potential partner.

When they did, there were judgments and attitudes. Since that simple dating and finding a healthy joyful relationship, it's entirely possible. I finally figured out how to do this. I have been with my husband for over 15 years now.

The key is simply keep trying. You need to go for what you want, despite the heartbreak and rejection. Believe in your potential as a dating and relationship partner. I know that sounds very simple and it's not.

That's why I created Dating Made Easier, the monthly membership that will teach you how to get the results you want, feel more comfortable and confident dating, and give you consistent support with monthly workshops, brainstorming, and networking. Go to [radiantabilities.com/datingresources](http://radiantabilities.com/datingresources) and join today.

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**Keith:** Let's talk a little bit about that and maybe those points on that map that are lost. You've already touched on some of this in the general sense. What are some of the specific problems with Florida's response, the Florida Specific Youth Survey?

What are some of the key differences between what YRBS and the FSYS track and report on and what that might mean?

**Caitlyn:** I'll speak to this briefly and then give others a chance. This is Caitlyn. I was part of the work group that was selected to help develop the Florida Specific Youth Survey. I was very concerned about the elimination of the YRBS and have a real interest in making sure that whatever was going to replace it would be valuable, as valuable as the YRBS.

Through that process, it's pretty evident that the new Florida Specific Youth Survey, is what it's being called, is incredibly different. It's measuring very different things. Entire topics that were on the YRBS are missing entirely.

The YRBS asked about teen dating violence. It's nowhere in the FSYS. The same thing about gun safety or guns on campus where it's...There's many issues that are going to be affected by losing this data.

We're not asking kids about guns on campus. We don't know whether the gun safety laws or the school safety laws that we are passing each year are actually making kids safer on campus. Entire topics of questions. Then as Nadine was referencing, this demographic information is missing.

The YRBS asked kids about whether they identified as LGBTQ. You were able to use the data to compare different groups of kids against each other and see are LGBTQ kids experiencing more bullying or less bullying, more teen dating violence, or less teen dating violence. Any of the things the survey measured as compared to their peers.

That again, helps you target a narrow where you're going to spend limited resources to improve the lives of borders kids. Taking out these entire swaths of information, the entire topics, there's nothing to compare back to the old data. We've lost all that longitudinal data.

We're just not seeing these kids. We're not seeing these issues in order to be able to address them. It's a fundamentally different survey and those few question...It's fine if we want to understand resilience about kids, this has at least promised to do so but it doesn't give us, as Caitlyn was saying.

Even in the instances where the topical area is the same, such as nicotine use and things like that. The wording of the question is not the same between the YRBS and this one for no apparent...Which would've maybe would've given us at least some little bit of continuity across the measures.

The wording was changed for no apparent reason, and definitely in ways that don't inform us about the wellbeing of our kids.

**Norin:** Even the process of how the new survey has been created, opaque is a generous way of describing that process, and there's no comparison. Here's an example. In 2021, one in six high school students reported that they were bullied either through social media or at school.

That same year, 22 percent of high school students and 45 percent of students who identify as LGBTQ reported seriously considering suicide. Now, when you look at the data, even when you factor in COVID and the negative mental health impacts of that isolation, how LGBTQ students were doing was even worse.

Knowing that becomes important. If you actually give a damn about saving the lives of young people, if you care about making school a safe place, a resource for young people who may have no other resource of support, all of that information is critical. You would not think for a second, "Yeah, let's stop measuring that," if you cared about young people.

I think the alarm that this sets off is not simply that this important tool has been removed. It points to a level of callous disregard for the well-being of young people. That ought to be a wakeup call for all of us about what is happening right now.

**Nadine:** Yeah, absolutely. That's why, a year ago, when we found out, a year ago, March, that this was in the offing, we got together a huge coalition of statewide advocates and people who really shaped the public health policy that safeguards children and youth, and especially kids who identify as LGBTQ, because we already knew that they were suffering mental health...

[audio skips]

**Nadine:** ...anxiety, depression at higher levels even than their peers. People from different sorts of organizations came together to say, "Look, we use these data every day in our communities and in our states, and we use it to improve the lives of our kids and protect our kids.

We will have no possibility of doing that if we withdraw." The outcry and the diversity of voices was really telling in that regard.

**Caitlyn:** Another difference with this new survey that is important is what the questions are asking and the way they're worded. The YRBS asked kids about the experiences that they were having and the behaviors that they were engaging in.

The vast majority of the questions on the FSYS that are about the same topics as the YRBS mental health questions and those sorts of things are about what they know. Not what they're actually doing.

An example would be asking, "Do you know about abstinence-only education?" Sure, I know about that, but are you practicing abstinence? We don't know this. The Youth Risk Behavior Survey was measuring risky behavior and the experiences of kids.

Now, with this new survey, we might be able to understand what the kids are being told, what they're being taught. We don't know what they're actually doing.

As a parent, and as a person who was formerly a teenager, we all know that kids sometimes know something is bad for them but they do it anyway. That difference is key to me, the fact that we're not measuring as many behaviors.

Then another really big difference is the focus on resilience, and Norin mentioned this, but the state of Florida has shifted or has created a little program about resilience education. Resilience is important. It is an important character trait. It's important for kids, it is a great protective factor for kids who are having difficult experiences, but it is not the same thing as mental health.

Outside of this survey, the state was required to provide five hours of mental health education to children each year in its public schools. That five hours has now been shifted to resilience education. Substituting one for the other, I think, is unwise. You can't just be resilient and have that address all mental health issues in the state.

Mental health issues don't just come from having difficult experiences and not being resilient in the face of those difficult experiences. Sometimes it's chemical. It's a brain imbalance. You can't resiliency your way out of a chemical imbalance.

Replacing the focus on mental health with a focus on resiliency is short-sighted. These kids should be taught about both, for sure. Mental health education is extremely important. Resilience is also very important.

We know this from studies about adverse childhood experiences, that resilience is very important, but it's almost offensive to imply that mental health is some sort of character flaw by suggesting that you can grin and bear your way through it, and if you can't, then you're somehow not a resilient person.

Let me say it this way. This is replacing actual mental health support with a walk it off mentality. Introducing this, the DeSantis Administration said we are rejecting the term mental health and we're replacing it with resiliency.

While they're at it, we're rejecting trained, skilled mental health experts. Instead we're going to get parents and coaches a couple hours training so that they can "ease the burden" on school counselors. No, it's not your...

I can't think of anything more irresponsible at a moment of great mental health crisis when the last youth risk behavior survey has told you young people are in crisis and saying, "You know what we're going to do? We're going to get rid of that foolishness. We're going to replace it with some, pick yourself up by your bootstraps, walk it off."

It is absolutely unethical what they are doing. Gutting the YRBS was a necessary step before introducing this absurd replacement for actual mental health support.

**Keith:** There's so much that's going to be lost because of this. It's astounding to think of the impacts that this is going to have. What about other types of disabilities? Would things retract before regarding youth with disabilities that is now noticeably missing from the FSYS? Are there other ways to get that data?

It may not compare directly with YRBS data, but do we have other options or are we just out of luck now?

**Caitlyn:** The YRBS never asked the kids who took it to identify whether or not they were disabled, so at no point were we measuring the impacts of our policies and what's happening in our state on kids with disabilities versus the general population of students.

That's not changed in the Florida Specific Youth Survey. They're still not asking that question. By removing entire topics from the survey, that's giving us less information about behaviors that can lead to disability.

For instance, not wearing your seatbelt. If you don't wear your seatbelt when you ride in a car, you're putting yourself at greater risk for becoming disabled if you have an accident. That's the way that it has related in the past.

Some of those topics remain, some of them don't. We're cutting out a piece of the pie as far as being able to understand the things that kids are actually doing in their lives on a day-to-day basis that might lead to disease or disability.

On this note, I will say as a member of the work group, I asked about making sure that this survey was accessible to students with disabilities. Making sure that their sample population was going to be representative and include kids with disabilities as the responders to the Florida specific case survey, and they had made no contingencies for making sure the survey was available whatsoever.

I was told later that they believe that this new survey is an improvement on the YRBS because the YRBS was pen and paper, and this new survey is administered on an online platform that they say is compatible with screen readers. Which is great for kids who use screen orders, but what about all the other types of disability?

Kids who need test taking accommodation in order to complete a test in school? Are they being given accommodations to complete the survey to make sure that they are included in what information we are getting.

Having it be a screen reader accessible is great for people who use screen readers, but what about everyone else?

**Norin:** Let's be crystal clear. The State of Florida did not pull out of the YRBS because of its lack of accessibility. People would've rallied around the idea of expanding access to it. You can compare and contrast Florida and Colorado.

Colorado created their own version of the YRBS. It incorporated the existing YRBS and expanded it and went on to include gathering more information on disabilities so that they could be more responsive to the communities impacted.

That's what you do when you actually are motivated by concern and care for students. That is not at all what Florida has done, and if the state of Florida said we want to rally the nonprofit world, the foundation world, and we want to see the CDC do the YRBS in a much more accessible way, and we want to see the expansion.

They could have an army of organizations and individuals from the state parents, we would all have been in lockstep. That is the exact opposite of what Florida is doing.

The harm that is being inflicted on young people, on students, we cannot skip past that because the entire purpose of this was to say, "We no longer wish to measure impact of our actions on you, the harm of our actions upon you. The only way to hide the impact is to eliminate the tool that we've been using to measure it."

We're also eliminating the ability to measure benefit, beneficial impacts of policies and laws that are being passed to help people. Just to be fair, I did want to note that there are two other surveys that the state administers previously alongside the YRBS that do provide some additional information and those will continue.

There's a tobacco survey and I think a substance use survey. Those continue and that information will still be available though I would, again, we're still not going to get that deeper information that we can drill down in on based on demographic and see the differences among different subgroups of kids with those surveys.

**Keith:** What do we do now? Are there any next steps? Is there something as advocates we can do? Or is there anything that maybe families of youth who might be disenfranchised by this data not being collected that we've discussed can do? Where do we go from here?

**Norin:** I think that this podcast and everything we can do to educate people, because most people do not know the initials YRBS. They did not know when the Department of Education took down anti-bullying resources. They did not initially know when books started being banned. They did not know a lot of these things until there was whistleblowers and public exposure.

When parents understand what's being taken away, and I say this as a parent of a soon to be seventh grader, when parents come to understand what has been taken away, what is happening and the impact it can have on their kids, they start showing up.

We are seeing it in school board meetings all across the state. Where parents who have never been politically engaged are showing up and they're demanding answers about changes that have happened over the last year.

The more parents understand that they didn't just stop a survey that helps track what's going on with young people in school, they have also potentially cut off access to resources to address those issues, whether they come from the federal government or from foundations, or from nonprofits that work for the wellbeing of young people.

We have a massive education challenge to help people understand what the YRBS is, why they need to care about it, and what impact it will have on their own children, and why they've got to

raise their voice and demand that the state reintroduced the YRBS, eliminate this political gamesmanship with these important research tools.

People are really tired of the politicization of things that ought to simply be the science of them, ought to be focused solely on how do we get the best information in order to provide the best support to maximize better outcomes for young people. Those should be the only considerations.

Unfortunately, going to war with the federal government, playing all these political games have absolutely muddied the waters. We've got to make sure that people understand what the stakes are.

**Nadine:** Absolutely. Awareness and education are paramount. Connecting it to the resources that are available to students and families is critical. We didn't really talk about the six school districts who have their own YRBS surveys, relationship with the Centers for Disease Control.

Actually, they have clinical dollars for sexual disease screenings, and pregnancy prevention, and very specific interventions and prevention services that help kids. Those services are at risk because of this withdrawal, because they've all received letters from the state DOE not to participate in the YRBS anymore.

The relationship to resources, I can't underscore that enough. Just calling for the reinstatement because how do we get these data back that give us insights to kids, in general, and groups, in particular, that are at risk of great harm?

**Caitlyn:** Yeah. It can be exhausting with all of the various things that are going on in our state. There are so many high-pressure issues going on. I understand some people are differently resourced energy-wise, money-wise, time-wise, so I would just encourage people to do what they can and feel good about that.

If you can go to school board meeting, then go. If you can't, write a letter. If you can't do that, hug a teacher. Whatever you're able to do, because we all need to get together on this.

There is value in going back, even if we don't start doing the YRBS again for another year or two. There will be a gap in the database, but we would still get good information longitudinally to be able to compare the future to the past.

This is not a lost cause. It is important that we do get back into the many states that participate in the YRBS. Echoing what Nadine said and what Norin said about really just making sure folks understand that whatever they can do is the best thing that they can do.

**Keith:** That is good. I'm glad that there is a, hopefully, positive side to this where changes can be made in the future and we can get this data being recorded again and useful.

I do hope that this podcast episode is helpful to those who listen to it and learn about what's going on here, because y'all made a good point, people don't really know that these surveys even exist and have never really thought about it or cared about it so much, but now you're listening to this and can be a voice to hopefully get this back.

I really do appreciate all your time today Caitlyn, Norin, and Nadine. Really glad you guys could share your insight on this and to help educate our listeners.

**Caitlyn:** I also want to thank you Norin and Nadine for accepting our invitation. It's been very nice to speak with you this morning.

**Norin:** I appreciate the invite and working with all of you.

**Nadine:** Thank you. I appreciate being invited. Take care, everybody.

**Keith:** Thanks again to Caitlyn, Nadine, and Norin for being on today's episode. It was really insightful, and it's so important to learn so much about this topic. We will be keeping an eye on things, watching how they develop, and we will keep our listeners informed.

**Maddie:** Certainly, I learned a lot, and I'm definitely am intrigued to follow the issue a bit more as time goes on. For those who are interested in learning more about the surveys or our guests can check out the show notes for links and more information.

**Keith:** As always, stay tuned for our next podcast. We have new episodes every other Thursday, available on all the streaming podcast platforms. Please take a moment to like, rate, subscribe, and share the "You First Podcast." We want disability issues to be better known and discussed, and this will help us do so.

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