



SIP and Sam Inclusion Coffee Talk

Podcast Transcription

Guest Speaker: Amanda Lukoff

00:00:07 Janelle Mercado

Welcome inclusion allies! You are listening to the SIP and Sam Inclusion Coffee Talk, a collaborative conversation focused on creating inclusive opportunities for all students. This podcast is brought to you by the Supporting Inclusive Practices project, SIP, and Changing Perspectives. We are your hosts, Janelle Mercado, and Sam Drazin.

00:00:29 Sam Drazin

A special thank you to the California Department of Education for funding this project, along with the El Dorado and Riverside County Offices of Education, for their ongoing support of inclusion for all students, including students with disabilities. If you are committed to being an inclusion ally, this podcast is for you.

00:00:50 Janelle Mercado

So I am thrilled to introduce our next guest speaker: Filmmaker Amanda Lukoff grew up advocating for her sister Gabrielle, especially whenever she heard the word retard(ed) (which is so hard for me to actually say in this bio)! With her feature film debut *The R-Word*, she unravels the history and lasting effects of this word through the lens of the sibling experience, captivating animation sequences, and self-advocates speaking truth-to-power – ultimately making the case for why the conversation surrounding people with intellectual and developmental disabilities needs to change. *The R-Word* is an unflinching, heartwarming, humorous, and hopeful journey through our shared human experience. *The R-Word*, premiered at both SXSW Education Conference and the ReelAbilities film festival in 2019 and later received educational distribution with Women Make Movies in 2020. Amanda was a recipient of the 2019 Champions Award from the National Inclusion Project for her work and advocacy. Amanda lives in Arlington, Virginia with her husband and two young daughters, and is a proud agitator and activist for racial & social justice. Amanda, thank you for being with us today.

00:02:09 Amanda Lukoff

Ha, Thank you so much. Thank you for having me!

00:02:12 Janelle Mercado

I was trying to think of ways to summarize my reactions after watching the film, *The R-Word* and it's a combination of so many experiences. I felt like I went through a little journey of being inspired, crying, (so yes, get your tissues before you watch the film) but also hilarious – laughing so hard at the end. And for those of you who haven't seen it, you have to watch it to the very



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end. So I'm dying to ask you, Amanda: just share a bit about your journey in making the film what inspired you and how did you get here.

00:02:49 Amanda Lukoff

Well, thank you so much for your kind words about the film. Now, I hope that all of that, when folks watch it, that all of that comes through the, you know, not just the you know the humanity. But also the humor because there's if there's not humor in life, I mean what are we? What are we all doing here, right?

So as far as my inspiration for the film. For those of you that haven't seen it, I grew up with an older sister with Downs syndrome, Gabriel. And our relationship and her being in my life definitely is just, like single greatest learning experience of my life, no question. And so kind of once I discovered my passion and interest in film and media, I knew that I wanted to do something that was inspired by our relationship. I mean people say when you know, especially you're going and making a documentary film, that you want.. You want to make something that you have access to, something that you're passionate about. So when the idea came, I wasn't sure if I wanted it to be.. how personal I want it to be. If I want it to be about literally, about me and Gabriel, about our family. Uhm, and so after I started doing some research um and I kept, the stories that kind of kept resonating with me were sibling stories. That wasn't an accident, right?

That's the ones that I experienced the R-Word through, and I also voracious documentary film watcher. And I've seen over the years, you know, different films about specific disabilities, different films about specific individuals with disabilities, but I had not seen anything that really confronted language and the power of language and how you know language impacts our attitudes and then vice versa, our attitudes impact language so, um you know, that's kind of when the idea came about and we're talking about back in 2009, the idea came together, but it took another five or so years and just kind of doing research off and on before I could start like preproduction.

And we did a crowdfunding campaign, raised \$50,000 so we could hire a cinematographer and we flew cross country and filmed with a bunch of self advocates and families and different thought leaders all over the country. Then we took about a year to put together a rough cut of the film. And I got pregnant, so we're like: we gotta finish this before I don't have any time on my hands! So we were able to finish that in 2019 and then premiered at South by Southwest EDU, and at the ReelAbilities film festival and, um, the response has been overwhelming. I mean, the film's been seen all over the world as far as Singapore and Australia. We've been seen at universities and hospitals and advocacy organizations and um, and that's actually how I met Sam! Was at South by Southwest EDU back in 2019. So it's been one of the greatest joys and gifts of my life, and, um, I don't know. Sometimes I'm like, I can't believe that we actually did it, like it's here, and it's it's impacting people's lives. And it's, it's making a difference.

00:05:53 Janelle Mercado

What I also appreciate so much about the film is the various perspectives that are coming into the documentary or the voices that are being lifted. We are talking so much in our podcast series how important it is that we are lifting up the voices of the disability community, and that includes individuals with disabilities and their families! Because it is such a unique perspective!



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We did a podcast with Emily, eh recently, and we're talking about how unique the experience is for each individual, but there is also these collective themes that come through. And what I noticed being the collective theme in the film was every single family member and every single sibling said: I just want to be understood, and I just want to live a quote unquote, whatever normal life! Like, do activities that everyone else wants to do; go camping, go biking, go swimming and I just, I really appreciate that perspective from the family voices also.

00:07:00 Amanda Lukoff

Well, thank you for pointing that out. You know, that was really important when we were, you know, putting the film together. And wanting to make sure that folks like my sister, and other individuals with disabilities, that that not only that their humanity was really shown and highlighted in film, but to kind of show, you know, the nuances of that. And the fact that, you know, just like, uhm, folks, you know, people of color, people on the LGBTQIA um spectrum that they, you know, they're not a monolith, and individuals with disabilities also are not a monolith. So my sister's experience, which you know, I think another reason why I want to show it, is because she's, she's lived quite a life! She's done things that are, you know, that, that that folks that are neurotypical or do not have a disability, you know, we have and we go through. You know ups and downs in our lives, so it was really important, um you know to show that to share her story and um you know there's a part in the film where she says 'I just wanted to be treated just the same as my sisters' and just, you know, something just that simple and that she felt that growing up and we felt that for her. So I think a lot of times people, people haven't been exposed to it, don't have the gift that we have right to know and love people with disabilities. So wanting to you know, to distill it down to this, wanting to be treated like everybody else, I think, was really important.

00:08:33 Sam Drazin

To kind of piggybacking on that, Amanda, I think one of the things that's so important for our listeners to really be reminded of is that disability is essentially the largest minority in the world, right?

00:08:46 Amanda Lukoff

Yup

00:08:46 Sam Drazin

Everybody knows somebody, whether it's a friend, whether it's a friend who has a sibling, whether it's a.. you know, everybody is connected to disability in one way or another! And one of the pieces of your film, which I think is really kind of important is, kind of, recognizing the sibling relationships and I'm wondering if you could tell our listeners a little bit more about you know, what are some examples of ways in which inclusion matters and benefits everyone? How would we do things in inclusive way it doesn't just support individuals with disabilities, but perhaps supports their friends, their families, etc.

00:09:27 Amanda Lukoff



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You know, I think that there's some data that I've you know, came across when I was in production of the film that siblings of individuals with disabilities learn empathy at a much younger age than their peers that do not have a sibling with a disability. And so you know, I think that siblings are kind of the perfect model for why inclusion not only matters but why inclusion works because there's no question that my relationship with Gabriel made me a more compassionate, more understanding person and, and it really informed how I see the world, how I interact with the world.

So kind of on a very fundamental level, inclusion can really open everyone up to understanding our shared humanity and why it's important that maybe we don't learn the same. Maybe we don't walk the same or talk the same, but I think that once people have exposure and have an opportunity to go to school with, live next to, work with an individual with a disability I think: one, they realize they're not that different than anyone else. Two, there's a lot that they can learn from someone with a disability. Three, that they are just like everyone else and deserve the same respect and the same opportunities as everyone else.

Everyone is only as limited as you know, the opportunities that they are afforded. And so I I firmly believe I mean, Gabriel was fortunate enough to go to to school with, we had the privilege my parents were able to, to pay for her to go to a boarding school for exceptional children and she went through school and and got a job in the opening community. And then, what, you know, lived in a group home and got a competitive job and was traveling and doing all of these things, and so we thought it was really important growing up to treat her like all of us. No one walked on egg shells. We cursed at her, she cursed right back at us!

I think my point was just that, if you want kind of the perfect example of why inclusion works, and why inclusion matters, you look no further than, than siblings. And why I think highlighting the sibling stories and the sibling relationships in the film, kind of, one of the criteria that we're looking at for the for the families that we followed, was that a sibling advocate that did something exceptional because of their relationship with their siblings? So one of the siblings does triathlons with his brother who has cerebral palsy. One of them helped co-found a camp for individuals with Downs Syndrome. And the other one helped to have law, the federal and state level laws changed to take the R-word out of laws. And that's just a couple of examples, so I think that, did I answer your question?

00:12:03 Janelle Mercado

I think with what you're really highlighting is not only how exceptional it is to be a sibling and the benefits gained in just having that love and compassion and nurturing and empathy, but also what I hear you highlighting, and I think is so important to think about in inclusive schools and inclusive societies is: we all have something to learn from each other! There is something so valuable about learning that we all have different and that is 100% OK. Right?

00:12:38 Amanda Lukoff

And we all have value. That's the other thing, right?

00:12:40 Janelle Mercado

Right!



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00:12:41 Amanda Lukoff

Like we all have value. Everyone has value and everyone should have the opportunity to be heard and to have a seat at the table. And I think that if those that are the most marginalized, if they are taken care of, if they are healthy, if they are treated with respect, then everybody obviously is, right? So, so it's like making sure that, that, like I said that they've a seat at the table, then I think that that that benefits everybody in so many ways.

00:13:08 Janelle Mercado

We've talked in our other podcasts about fear of having conversations and misconceptions about the disability community, what do you think are still some of those large misconceptions about people with intellectual disabilities? I know this is something in the film that you were really trying to extract and highlight

00:13:27 Amanda Lukoff

Yeah, and that's a great question. I think that in one of the ways that I was trying to maybe dispel some of those misconceptions was just by highlighting my, my sister Gabrielle. Because like I mentioned earlier, there are things that she has struggled with that everyone does! Whether it's struggling with your weight, being in a relationship that might not be the best for you. Wanting to be, have a companion, but having challenges there. Challenges with your job, so you know those are things that we touch on and that she talks about in a very just direct way like this stuff happened to me.

And I think that you'd be surprised even though we have come a very long way in, you know, in recent decades, but we still have a long way to go. People with disabilities you know are some of the most dehumanized and marginalized individuals in our society. But I think that our people would just have no idea how truly intelligent she is how funny she is, how what a hard worker she is, so I think that I wanted to, I mean, I wanted people to hear self advocates speaking for themselves.

I think that's another thing: I think that I don't know if there's necessarily a plethora of opportunities for people with with disabilities to really say, hey, this is how I feel, this is how, for instance, the R-word affects me, how it impacts me, how it makes me feel. I am human, I deserve respect. So that was another reason why we wanted to have self advocates in the film. Speaking directly into camera, looking straight at the camera and and saying that. So it's like I'm not saying it, listen to to, you know my sister saying it for for herself! So I think that misconceptions being that they're not that they're not smart that they don't work, that they don't maybe want to be in relationships or that.. you know there's a lot of misconceptions about people with disabilities that or people with Down Syndrome that they're all so sweet and simple.

00:15:20 Sam Drazin

I think you hit on a lot of the misconceptions, Amanda, and it's great to hear you share from that sibling perspective because it's the same sort of themes that Janelle and I have heard from other guest speakers on this podcast series. This kind of invisibility, where people don't see people with disabilities. This idea of dehumanizing them, you know that people with disabilities are less



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than people without. This idea of treating the disability as if it isn't there, but seeing the person in a different way. So I think you've hit on a lot of the ones that we've heard pretty consistently.

I want to kind of bring the conversation back to the film here because, you know, I've had the pleasure of watching the film several times and and working with Amanda on some projects around the film and every time I watch it, something else strikes me. I leave with a new thought. A new, ah-ha moment a new sort of hesitation and I'm wondering, like straight from the mouth of the filmmaker, Amanda, like what are like the three things that you really hope people walk away from watching the film?

00:16:33 Amanda Lukoff

Ugh, that's a good question but it's hard! OK, so I think that it's it's something that I've I've said kind of numerous times during this conversation is one, to walk away seeing and hopefully understanding our shared human experience, right? That we all are part of the same human family, um, regardless of you know if we are neurotypical or have a disability, I think that that's that's one. So humanizing my sister and and other individuals with disabilities.

I think another take away definitely would be the power of our words and the fact that people might not think, I mean, now that the word retard or mental retardation is not, technically not not the medical terminology for an individuals with intellectual developments and disabilities. I think that the fact that there is a disconnect with especially the kind of the youngest generation that we have who maybe didn't come up with the word but but it lives in, you know, social media, films, TV, music, literature. It's it's still very ever present, but I think there's a disconnect behind the fact that that word has so much baggage and history behind it, and I believe cannot be disconnected from the individuals, the community that is so closely connected to it. Hopefully everyone think taking a step back after watching this film and thinking about like thinking before they speak. I know it's very pie in the sky, like, can't we all just be more kind? But at a foundational level like, that's is kind of what I want people to think about!

Putting the film together, we filmed like I said, off and on for three months, we filmed hours and hours and hours and you know, we had to whittle it down to 60 minutes so there were some amazing interviews, and clips from interviews, and nuggets of conversations that weren't able to be part of the film. And one of them was an an individual thought leader that we had in the film named Jabari Asim, who wrote a book called The N Word. And he was lamenting the fact that when folks come up to him, maybe about the n-word, and they're like, 'oh, what what's the big deal? I don't mean anything by it.' He always says, 'I think that you're struggling from a lack of imagination like there are how many thousands of words in the English language and you're stuck on this one. And you know that it's it's causing harm. It's detrimental to to folks and and and their loved ones, like, why would you still want to use it?' So anyway, that's just one like amazing nugget that we weren't able to include. But words matter and, and words are powerful. So that's number two.

And then number three, I think, I hope that after watching this film that folks see the important like S-E-E my sister. Right, to piggyback off what Sam said? See like, see folks with disabilities and and something as simple as like just waving or acknowledging them, giving a nod saying hello goes a long way and people might not know that. But for a long time people disabilities have not been seen. And like you said Janelle, the kind of, one of the themes that kept popping



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up through the film is in the self advocates and their families wanting to just live a little life their own life, just like everyone else. And I think being seen and heard is it is something that they also really crave.

00:19:56 Janelle Mercado

Amanda, I loved some of the research that you highlighted in the film, and one of them being that you know, talking about the number of people and those who have heard others use the R-word. And how it's being used and the fact that nine out of ten kids said, 'yeah, we hear it all the time', but then two out of ten said 'oh yeah, I use it'. But no! And then, I think what was really fascinating to highlight is taking that research to the next level of how many people interrupt the ableist thinking-

00:20:34 Amanda Lukoff

Yup!

00:22:34 Janelle Mercado

And conversation when you do hear the word, or you do hear people with ableist thinking talking about individuals with disabilities in, from a deficit model? From a deficit thinking of less than or othered. I mean, yeah, do you have some.. after doing after doing all the work that you did to create this brilliant film? Do you have some suggestions for our listeners on how to engage in those conversations? How to interrupt the cycle? And really be that ally for individuals with disabilities.

00:21:08 Amanda Lukoff

That's such a good question, and it's such a challenging question because even now as an adult, I mean, it wasn't easy when I was a kid when I was a child. Like, speaking up for, you know, in defense of my sister against that word 'cause that was, I say like that you know, whenever I heard the R-word and spoke up about it, I mean that was kind of the, my earliest instances of being an advocate for my sister. And then I said, this film is kind of a continuation of that advocacy, if you will, and and so it wasn't it, wasn't easy then and it's not it's not easy now. Um, and I don't have the right answer.

I can tell you that I asked Loretta Claiborne, who's one of the self advocates and thought leaders and just an incredible human being who's I refer to her as the the godmother of the R-word movement. I mean, she's she's gives the sticks and stones talk at schools, and has done it since the 80s. She's a global ambassador for the Special Olympics, and it's just a world renowned speaker and a Special Olympics athlete and just an incredible human being. And one day 'cause I kept getting that question, and I called her and I was like, Loretta I don't, I don't, I don't have the the perfect answer. What would you, what would be your advice? What would you? And she said something to the effect of: It almost doesn't matter what you say, it's it's the fact that you're saying something, right? Like that's half the battle is to, because so many.. have so many of us, and I'm probably guilty of it too – like when you hear it in the moment you're like, oh oh, it's just it's not, it's oh, they just walked away. Like it's, you know, it's never convenient, it's never easy, so I think she was just trying to say that that because that is as hard as it is. That like, just speaking up in general, it doesn't matter what you say, but that's the most important thing.



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Um, but I, I have young children and so I always think, and I always say to them and say to their friends and and other folks who kind of asked me about this, is like go put yourself in someone else's shoes. And Connor Long whose brother Kaden, they're the sibling duo that did the triathlons together and Kaden has cerebral palsy. But Connor said in the film, 'you know that if you put yourself in someone else's shoes, then you can really start to understand why why words matter, why you you know a word like that dehumanizes individuals with disabilities. So that's kind of my, you know, I would say. Just not, you know, I don't want to make you feel bad or anything, but that word it's really hurtful and so that's where I would start.

Do you guys have any, um, you know, advice as far as when that happens, when you're like... what, what's works for you for either one of you. I'd love to know.

00:24:06 Janelle Mercado

I I would say, uhm for me, I, I personally cannot go on in the conversation without addressing it.

00:24:16 Amanda Lukoff

Yeah!

00:24:17 Janelle Mercado

That's just me, but um, I feel that I have the privilege to use my voice and to have had so many amazing experiences to learn from individuals and families from the disability community to be able to deeply, deeply understand why the language is so hurtful.

00:24:38 Amanda Lukoff

Mhmmhmm

00:24:38 Janelle Mercado

At the same time, it doesn't always make me the favorite person in the room and that can be a challenge. Even within my own personal friends circle or family

00:24:50 Amanda Lukoff

Yeah.

00:24:50 Janelle Mercado

and people who are just not as... I mean, it's not.. Sadly, it's just not necessarily common language

00:24:57 Amanda Lukoff

Yeah



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00:24:57 Janelle Mercado

for people to or I should say the opposite is unfortunately, it's still too common.

00:25:03 Amanda Lukoff

Too commonly, huh?

00:25:04 Janelle Mercado

It's too commonly used, and so immediately you get the response of, well, I didn't mean it like that.

00:25:11 Amanda Lukoff

Right, right

00:25:11 Janelle Mercado

I didn't mean to say something mean and it's like no, I know you didn't, but here's what that actually means. So right

00:25:20 Amanda Lukoff

Intention versus impacts, yeah.

00:25:21 Janelle Mercado

Correct! Absolutely, perfectly said!

00:25:24 Sam Drazin

I think it's that idea, you know, in a previous podcast we had spoken about the idea of ableism and within ableism and ableistic perspective. I like to break it down with intentional and unintentional ableism, right? Just how, there could be intentional and unintentional racism so I think the you know, I think one of the things that I really stood out in the film for me is all of the examples of unintentional ableism, unintentional harm, unintentional negativity through the use of the R-word. Whether it's in conversation, whether it's in media and songs or comedians.

00:26:06 Amanda Lukoff

Mhmhm, yeah

00:26:07 Sam Drazin

Um, Amanda, we are coming to the end of our time today. Um, thank you so much for, for, I'm loving your bio that you put the word a proud agitator.



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00:26:18 Amanda Lukoff

Yes!

00:26:18 Sam Drazin

So I want to thank you. Thank you for being a proud and active agitator in the world. And really helping people realize the negative impacts that this word has and the history that this word has and the way that we can be better aware and shift our mindset and shift our thought process around how we can use language in a way to cultivate more inclusive societies, rather than continuing to perpetuate an exclusive society. For all of our listeners who are super intrigued and on the edge of their seat and want to know how they can get access to watch your brilliant film. How can our listeners see your film?

00:27:05 Amanda Lukoff

Thank you Sam. Um, I I before before I let everyone know. I I I just wanted to add that I think that you know, difficult conversations, right? It's sometimes, that's the starting point. Some people just can't like, can't even get past that. So so my hope is that this film that then that's the power of film and this medium is that. You know, it can approach and help really dissect and distill down messages of things like inclusion and why language you know how power the power of language. So I hope that, you know, this film it can, I think this film can help start difficult conversations and that's kind of one of the reasons I wanted to make it.

So just appreciate the platform, appreciate this conversation. Appreciate you all so much and the important work that you do, so thank you guys for being rockstars! And for those folks that are interested in in checking out the film or learning more about it, we have, please go to our website TheRWordfilm.com. We have a trailer on there, there's a little bit more information about the film. We were fortunate enough to get educational distribution with Women Make Movies and so they handle the day-to-day sales, and we're still kind of in the phase of getting licensing the film, but I think we are going to be doing... I think we might be doing a personal kind of DVD sales for this home use? But at a certain point, we're going to be doing streaming and stuff like that.

So please check out the website TheRWordfilm.com. Send me an e-mail, I'll put you on your information on our e-mail distribution list so you get updates about the film, but just thank you all for your time. And thank you all for helping to make the world a more inclusive place.

00:28:43 Janelle Mercado

Gosh, thank you Amanda! I feel like we could talk all day.

00:28:46 Amanda Lukoff

All day, all day long, all day.



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00:28:28 Janelle Mercado

Right, but thank you for being here and for bringing this film to us. It's truly a gift to anyone who watches it. So if you haven't seen it, check it out.

00:29:58 Sam Drazin

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00:29:22 Janelle Mercado

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