**Down to the Struts**

Season 2, Episode 4: Disability-Positive Education

Host: Qudsiya Naqui

Guest: Alan Holdsworth

Transcript by Ilana Nevins

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**Introduction**

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Hi, this is Qudsiya Naqui and welcome to another episode of down to the struts. In our last episode, we spoke with Dr. Roger Ideishi about the need to reimagine our educational, social, and cultural spaces to build access for children with intellectual and developmental disabilities. In this week's episode, we'll return to the topic of education but from a new perspective--we'll discuss the importance of infusing disability positive messaging and Disability History into K through 12 Education and the need to develop leadership capacity among disabled students on college campuses. We’ll listen in on my conversation with Alan Holdsworth, Director of Disability Equality Education--a Philadelphia based nonprofit dedicated to this very mission. Okay, let's get down to it.

Qudsiya Naqui:

Thank you so much, Alan, for joining me on the podcast today. Can you start us off by telling us a little bit about your background and how you came to found the organization Disability Equality Education?

Alan Holdsworth:

 Well, you'll get your listeners will know straight away that I'm not from America. I'm actually from England—Manchester, England. And I've been a disability rights activitst since the mid 80s, I would say, I've always been kind of interested in education. And in England, I was involved with a goal of disability equality and education, and also a group called ALFIE, which is the Alliance for inclusive education. So I was actually helping in Birmingham desegregate schools and nurseries with the Director of Education. So when I came over here, we started off by founding a group called ALFIE. And we actually did some demonstrations on the 50th anniversary of brown v. board saying it’s about time disabled people are not segregated in education, too. And we did get some money from the school district to look to how schools can become more inclusive. And then, well, almost four years ago now, we got some funding from Pennsylvania Developmental Disabilities Council to actually challenge the stigma of disability in education. Our approach was to look at how we can create lessons that include disability-positive messaging, and identify resources that teachers can use, and also like maybe creating a school calendar of events. So some out of the year, disability kind of pops up in the in the school curriculum in the school program.

Qudsiya Naqui:

That's great. Thank you so much for sharing that story. And it's wonderful that you were able to bring the work that you were doing in the UK here to the US. So can you dig a little bit deeper into the work of Disability Equality Education? I know, you know, when we spoke previously, you talked about the two areas of work, broadly speaking, one being working in K through 12 education, and then the other being organizing on college campuses. So could you share a little bit more about the programming that you provide? And kind of how the organization works with students and educators?

Alan Holdsworth:

Okay, yeah, so we have created a website. And on the website, we have lessons from k to 12, which been designed and developed and kind of approved by disabled people because we found out there's lots of stuff out there, but it's not all good. So we haven't been if we recommend the book, we've actually read it, andwe think , yes, this is a fair representation of disabled people. And then out from that this is a free website to go on and just download the lesson plan which is aligned to the state standards. So it's already kind of been approved by the state and some of them have been improved by national standards. And basically what we're trying to give the teachers a break from having to plan a lesson. So they just go on there, all the materials that teachers will need about on the website. We've even got to the point now where we've downloaded some books, and to PDF even, we're into the COVID era. So some people can actually download some of the books that we recommend. Some of them are attached to lesson plans. The other thing is that we've at the moment we're creating four exhibitions you see, we thing called disability arts a lot and we work with a group got another organization for which I also founded called Disability Pride Philadelphia. Through Disability Pride we've got our like contact with lots and lots of great artists in in all sorts of mediums like singer, songwriters, poets, painters, we can bring those artists into the schools to actually work with young people and we have money to pay for that we don't charge the schools anything, we actually give them money. We also take part in some schools are having a diversity fair quite often they have to think about disability as part of diversity, part of our diverse identities that we have. Now we actually participate in all of those fairs, we do presentations. And also at the moment, we actuallybecause , we've got COVID, and you know, kids are at home all the time, we created some of the lesson plans and simplified them. So the parents can teach the kids as well. So they can do that on their own. Most of those are around both. And what we're finding is why it's important to get disability into the curriculum. If young people begin to get disability that way, they become more informed that will help to reduce the stigma of disability and misinformation. And the against that a lot of us have grown up with around disability issues. So that's what we do on the schools.

And on the college level. Obviously, it's different in college, because everyone's like I said, countries are very different. So you have small campuses, you have huge campuses in colleges, what we try to do is create two things in mind. One is a calendar of events. And I'll explain what that means in a minute. And then the other one is to actually help disabled students form groups within the college so that they become part of the student government, you help them with all the bylaws, and then those people can then you know, access college funds, they can use the college auditorium. And we've done some really successful events through these groups. One of the things we've done for the last three years, a place called millersville University in the center of PA, we've got a really great partnership with them. And with the disability pride day, for the last three years we’ve had a display five, that is the sort of thing we did was we had a film with the filmmaker, we would have musicians performing during a concert, we did a march on the campus did an actual march around the campus. And there's a street called “Normal Street.” So we paused and took a picture. And then in the normal Street, we did some street, our 12 foot by eight foot Canvas, and then these little trays with paint in them. And what you do is you'd roll over in your wheelchair and make a picture. So we call that wheelchair art. But you could also use a cane. So we were using all these different implements, and then we just hung it up. And on the first one, we actually was doing very keen to do some sort of direct action in form of protest. So what we found was that the cafeteria or as the students would go for lunch, they have turnstiles which wheelchairs couldn't get through so that goes all the way around to do it. So everybody knew about it, the Provost knew about it, they had a teach-in about it. Well, we just did this like fold Fold test, and it was really kind of cool. And next year when we went it, guess what the turnstiles were now accessible. So had a really fun day and then the other student group came along and they had that T shirt, they made their own t shirts, and so on. So that's the kind of thing we've been offering other colleges as well. We also have like, at the moment, we are creating four exhibitions, one for each for elementary one for middle one for high and one for college is being commissioned by disabled artists to actually be both virtual but also once this is over, hopefully, there'll be standing those exhibitions in a sense, will help create a discussion. So for instance, in we did have one exhibition we've had opened by one of the colleges in Berks County Community College. This is like a 22 tile exhibition. The tiles are about two foot by two foot, just the history timeline of disability from way back. So I think we start off with like that sign language. And we end up with adapting dc in 2017 saving Obamacare. Everyone was saying it, I went to the cafeteria. That's where the exhibition was on that college itself. We got sponsors and both the groups and those around that Berks County have won the diversity award for the whole college initiative planning things like film festivals, which are going to be coming up in March last year we did on the International Day of disabled people, which is December the third if you didn't know, we did a thing called fly bait. And this was a worldwide event, you had at least eight countries tuning into it. And it was a whole day of mostly music with mostly disabled artists from all over the world. So we have such people from Singapore, from Australia, people from England, Germany, Brazil, they got thousands and thousands of people watching them the day as well as creating kind of a climate of, you know, kinda what promotes what we're really trying to do. So that disabled people and their issues are not invisible to the general public.

Qudsiya Naqui:

That's so fantastic. Thank you for painting a picture of the work that you're doing Alan. As myself as a blind person, we never learned about Disability History or talked about disability positive messages in school. And likewise, I never had this sort of mechanism and a resource to help organize students on campus. So your work is so important. It sounds to me. So right now the focus is on Pennsylvania, Pennsylvania school systems, and then also universities and colleges in Pennsylvania, do you envision this model being replicated in other states is that something that has been sort of going on and spreading based on the work that you've been doing?

Alan Holdsworth:

Yeah. To be honest with the website being free, anyone can acess it. People from all over the world have been using the website resource, of course we have measured in terms of our grants what we're doing in Pennsylvania, because it's a Pennsylvania grant. But to be honest, we've been working on this, you know, we know that other teachers are using it, we also post most of our lessons and some of our resources on a national website called Share My Lesson, which teachers use and we're one of their main partners. Now, they really like what we do. I think they have about a million teachers who have signed up on that site. So that's good. And then eventually, we're going to upload all of our lessons onto Share My Lesson, as well as our own site. And then on Disability Five. Because we are in the COVID situation, and we’re all kind to more colleges. So that means getting together on a zoom call. So just like what we're doing kind of right now, there are some colleges where there's only two people who are interested at the moment. But so they join in with other groups to be more successful. And basically, what you're building, there's a whole network of youth leaders of the future. And we're going to be digging into sort of I mean, we've been doing a lot on history.We’ve also been doing English literature and language, a little bit of math, I think what we want to do next is we want to start to begin to do advocacy training, will start to train young adults and kids a few skills about how to do that I prefer collective advocacy, community advocacy, rather than self advocacy. Because self advocacy helps a person, but that doesn't necessarily solve the problem as easily people solve problems when they work together and come together. So within the advocacy thing, we'll be talking about things like negotiation skills, how to cut an issue, did you know what cut an issue means? Or should I explain that?

Qudsiya Naqui:

Oh, please do explain.

Alan Holdsworth:

Okay, so let me start off with saying I'm concerned about stigma in education. Well, that's just too big to handle, see, understand what I say. So what I've said, Okay, so what do we do, right, they have advised and educated the politicians at the Capitol—I’ll be careful not to say The “L” Word her--to create, craft the bill, right? To go before the Pennsylvania Commonwealth, which will mandate all schools to embrace a disability curriculum. So now you're going from your concern, which is about stigma, and you’ve got it down to a bill. And then you could go out and find out who can give you what you want. Then you go to politicians to knock on their doors to get this campaign going. So you go from concerns if you break it down to something which is manageable, but is also specific by identifying the people who can give you what you want. And then go ahead and do it, that we will be teaching people how to do that. It’s probably more of a high school and college kind of thing. I think we could have some roleplay fun with even the kindergarteners.

Qudsiya Naqui:

Yeah, I think the concept of collective advocacy is so important. And just for our listeners, The “L” Word that Alan refers to is lobbying. So as a 501(c)(3) organization, which is a tax status here in the US organizations with that status have limitations on what they can do in terms of advocating with a legislative body about passage of particular laws, but I think it's so fantastic that you're arming kids very young with the tools they need to work together collaboratively build community and do advocacy as you described it. So I wanted to turn for a second to the K through 12 education and perspective of educators. Can you share a little bit about you know, what you think is most important for educators to do, what strategies are most effective to make sure that they're bringing disability education, disability history, disability pride into their classrooms and into educating both their disabled and non disabled students? So could you share some concrete examples of things that you found effective in the work that you've done?

Alan Holdsworth:

Yeah, I think one thing that's very misunderstood about the whole project quite often and it's been misunderstood by the federal government, to be honest, they think it's all about disabled people. It's our thing, but it’s actually the opposite. It's actually about the nondisabled people, who , never thought about disability, you know, at all. Our target isn't like actually disabled people. It's the non disabled people is the is the culture. I think what we're trying to do is change the school culture. And one of the things we did very successfully in England, there's a concept called the whole school policy. Should I unpack that a little bit?

Qudsiya Naqui:

Yes, please do.

Alan Holdsworth:

I think the difference between America and England in a way is that over here, you have a thing called IDEA. the Individuals with Disabilities Education Act, your whole focus and then the focus is parent driven right So it's mostly parents who are going to be involved in the activism, if not the young people themselves, those parents have probably just got as much stigma in them as anybody else, you know, in a way and also it's usually about the individual what inclusion seems to be in America, and I'm not saying it’s perfect in England by any means. I think the theory is your kid goes to kindergarten and the kindergarten Is good—they have special ed teachers, they have like speech therapists, physios, etc. And they'll get it to make sure that that kid is-- that the problem is then solved by what they do. So you know, if it's like you say, a blind kid goes into kindergarten, yeah, okay, everything's good. And then the blind kid gets into first grade and he goes back. So it's like a bubble, he's going through a bubble. So things improve as the students their particular situation, but then one staff isn't there. So they may talk about being blind in the in kindergarten, and then the next group hasn't gotten a blind person, they certainly don't bother talking about it. So it kind of thinking about it like that our whole school policy means that you're not looking at it from that kind of perspective, if you're looking at it from the actual school itself. And you're saying, okay, and when we say whole school, we mean whole school, we mean the bus driver, we mean not having segregated transport to get to school on the bus. I mean, all the people who work in the school, they are part of the plan, particularly the people who supervise playground activities in the breaks, that is a really crucial thing. That's where you make friends. So often, the first thing I do when I I have a look at a school is I go into a playground. And if I see a bunch of disabled kids against the wall, and everybody else doing everything else, I know that we got some things to do. So our whole school policy, every single aspect of the school should have some sort of disability component into it. And that obviously then includes the curriculum. And the activities that you do--don't go on school trips that aren’t accessible. Just some very simple things we’ve done like this one. This was this a k- 3 three grade in a school district. And we didn't do the lessons, but we wanted to observe teachers doing it. So we went up for a day and just sat there actually just watching them do this lesson that we designed, it was around a book called “Hello, Dog, Goodbye, Dog.” We chose that because the dog loves his kid, right? The kid said the kid goes to school, and then the dog follows him to school and just tears the school up—the principal's office, everywhere--he eats all the food in the canteen, and all that kind of stuff. So in the end, he decided to go to send him away to be trained to go to college, the dog. So the dog becomes trained as a help dog gets his little diploma. And then you know, he's very good and well behaved. And the whole point of that was that there was some young person who's coming into the school next year, who was going to have a help dog. So there was going to be a help dog in the school. So from k to three, all the kids then kind of knew the rules about what you can and can't do with the help dog and why they have a dog and like I have a dog. And so that was one of the ways in which you know that kid then had a positive experience from his peers.

Qudsiya Naqui:

I think that's really helpful to make this more concrete about some of the things that teachers and students and staff in a school can do drawing from my own personal story, I was a child who was bullied, so I had some vision, I have a degenerative condition. So I lost vision over time. And when I was in school, everyone thought I quote looked normal. I didn't use a cane during the day and things like that. But they didn't understand what it meant to have low vision. And so I would drop a pencil on the floor. And I would have to feel around to find it. And boys would make fun of me and call me blindy and it was really damaging. But you know, if we educated kids from very young age to be, quote, normalized to seeing disabled people and understanding that that's okay, that could have prevented a lot of harms for me. And I'm certainly not alone in that type of a story. So I think what you're sharing in these exercises can be so important. And I'm looking forward to sharing your link to your website so that educators who listen to this podcast can access these curricula and these activities to do with their students. So I think that's really fantastic.

Alan Holdsworth:

Give you a couple more examples, if you'd like me to just keep it on that kind of that subject. And there's another book, it's called “My Traveling Eye.” And it’s about a young person who has an eyepatch, and then gets teased too. So her mother makes it really cool. All the kids want this really kind of psychedelic eye patch. And that's another kind of book. A couple days ago, we did a lesson called “Dad and Me in the Morning,” which is about a deaf boy and his father who go for walks and watch the sunrise on the beach. It’s a really good lesson because on each page of the book, there's different ways that people are communicating. So people don't only communicate by speech, , they communicate by facial expression, as well as the things that some people use sign language, some people walking by a buzzer here, they hold hands, you know, there's all sorts of ways and we actually asked the young people to sort of read the book saying how many ways of communicating can you see in this book? The lesson being there's all different ways to communicate. And then nothing strange about people using sign language basically.

Qudsiya Naqui:

Right yeah. So turning, to the students on the college campuses. So we talked in, you talked a lot about giving students the tools to organize themselves. So I'd love to hear a little bit more about what strategies you think are most effective as you go on to college campuses and build the capacity of disabled students to organize?

Alan Holdsworth:

One of the things that I think people would think about starting this off is you don't need to start big, you can start small. So I mean, the Bucks County group started with four people in the whole college. Yeah, it's now grown to 24. Now, so it takes time for it to grow. Clearly, there's also a theme for our students. So you really need to have a good faculty member, at least one good faculty member who's interested in this work, because they'll be there probably longer than the students, if you'd like to students might be in the last year, and really good. And then that student leaves and it's like, oh, it's not a big number. So you have to have that partnership between the students. And the faculty. And faculty needs to want to do that. So we do have like about eight colleges now which have faculty members who are trying to help trying to help start groups and that there are different stages of development. I think the thing is that there needs to be a balance between what you would like them to do and then what they would like to do. So one of the things that one of the groups did was they did like an open mic night that they've also had a disability quiz, which I thought was really good. And they designed this, I didn't even tell them that they were designing this type. I think there was like 10 questions. I've got nine of them. Right. I thought I would get them all right. Do you know how many presidents of the United States have been disabled?

Qudsiya Naqui:

I don't know the answer to that. What is it?

Alan Holdsworth:

It's 11.

Qudsiya Naqui:

That's significant.

Alan Holdsworth:

including George Washington. So there you go.

Qudsiya Naqui:

That's like 20%. Almost.

Alan Holdsworth:

Yeah. When you think one of the guys who wrote the Constitution, yeah, he was also dyslexic, as well. So to dig into that. So the open mike night was really funny, because like some people are really good at singing. Yeah. And other people just said, you have to bring a challenge this young girl, she does handstands on the zoom. You know. And then some of it is about, you know, having things on campus that you want to change, we had a lot of plans for some openair events , before COVID hit, and it was really strange. So even though we can’t do them during COVID, eventually we'll get back in the classroom. And eventually, they can go and have an impact on the small, smaller campuses. I think on the larger campuses, we're talking more about just creating a programme of events. We're also having a support group. And one of the saddest things that happened was one of the students in one of the groups died of COVID. And that group was really, really, really supportive of the family and of each other. And wonder, why do you need a group? Well, that's, that was a very, very good reason to have a group, they had a memorial service team, the group had a T shirt made with his face on and stuff like that, and you know, in memory of, so some of its like, fun stuff, in some ways, not so fun, but they can bond, I mean, they meet every probably every three weeks, and they get to find a time when none of them studying. So that's always kind of one of the problems that they have. It's important, I think, just because what we're not asking them to do is form a little Club, which doesn't impact the rest of the college so that we can impact is not just to be sort of insular, you know, just being mutually supportive, which is great. But I think it also is about having things to do that are actually you know, in the colleges and some of these groups are actually quite open to having allies in the group. So it's not necessarily You don't have to be disabled to be involved. You just have to be led by disabled people.

Qudsiya Naqui:

I'm curious about you know, when you engage with students on a campus, you know, how long is your engagement before they kind of start to run themselves? I don't know if there is a typical timeline or and how have you observed the longevity of these groups once you kind of take a step back and let them lead and move forward?

Alan Holdsworth:

That's a good question. I think it's just don't really put a timer on it because people work in different ways. And what you're trying to do is if you feel the fall off I felt that they were like not quite getting there we were trying to be more involved and more involved What that means is one of the college groups they have a kind of what you call with that first week of college saying welcome to wherever it's like a fair and it's like a club fair. So all the different clubs they come and sign up for the club fair. So you know, I'm just kind of in the same room. So what we did for the disability club, we brought a disabled musician for a performance in this big room with all the clubs, and people were like, “wow, a disabled person performing,” and we signed lots of people on that day. And then of course that is about whether they have to do all the work in terms of keeping the group informed about what's going on. So we find that person or those people, that group of people in the group that are there to make sure that people are contacted about meetings, you know, if there's anything problems that face begin to do that, this is a great skill for them to get I mean, In terms of like college is a great thing to put on your resume, once you leave, it really just depends on each group. At the moment, the Millersville group know it's not going to be good at the moment right now, because we're talking a lot more with them at the moment says, you know, what asking you to do is COVID is hard. It's, you know, it's hard to be like on college campus each other. So just making sure that the faculty members are also advising them about how to do those events. So when we're doing the Film Festival, which Millersville is going to be part of, we will make sure that the disability clubs advertise at that point.

Qudsiya Naqui:

Yeah, and I love the point about having a faculty champion, I think that's really important, because they will stay on as the student cycle through the school. And they can develop a sort of foundational base and create longevity for a group. So I think that's a really, really important point. And I thought it was really interesting earlier, you were talking about how COVID has created this opportunity for student groups from different schools to connect virtually, and learn from each other and build a kind of bigger network. So I think there's been so much that's been unexpected about the pandemic. And I think there are challenges that you describe, like in terms of being able to be on campus, but then there's also opportunities, which is connecting with people you wouldn't otherwise because they're far away.

Alan Holdsworth:

So I think in April, when things are better think about when finals are going to do a Saturday in April, where we're going to have both faculty and students coming together from all universities that we work with, to talk about how they think or how that clubs going to, they're going to set up a club and so on. Yeah, and then have the young people talking about what they do in their clubs. And you can share the ideas about what your what these clubs can do, but you have to do something. So quite having a club is the only way to do it. I think young people have better ideas than we do to be honest. So we're really excited about that. I'm not quite set on a date for that. I think it's going to be wherever the second Saturdays and in April, something like that. I'm really excited about that. That will be likestatewide , I mean, anyone can any universities, any faculty know most is probably faculty members from the university getting involved in finding out what we do. That's gonna be really cool in terms of what we want to do for the rest of this project.

Qudsiya Naqui:

That's wonderful. And I really hope to see this model replicated in other states, you've had so much success in Pennsylvania, and so it'd be great to see it proliferate. I'm excited to see that happen. And I hope it happens at a national scale as well. So this has been such a great conversation, Alan, and I wanted to wrap it up by asking you what advice would you have for students on college campuses, educators, parents, how can we all work together to build a more disability conscious disability positive world for disabled people.

Alan Holdsworth:

The biggest problem as well, I'm going to answer that question, but the biggest problem in this is that stigma is about attitude. So now we know that to the social model of disability, you can split it down into environment, which is kind of easier. Now we'll take care of course, wheelchair accessible, transport, like those that's kind of like there. And you can measure that because you can say, Oh, well, that's all wasn't bad enough. Now, it is quite simple thing to sort you can measure it, you can say that the school has developed more inclusive practice. But what you can't do is because your attitude change is really hard. So what you have to do is actually, you know, create a climate of inclusion, basically, and you create a climate of inclusion, by having disability in all aspects of what you do. So I think the more resources we can put out there for parents for teachers, the more they have at their disposal, which they don’t have to create, because it's already there. From a national perspective, we did some research, we didn't want to reinvent the wheel, you know, when we started out there, or maybe some of the state has already got this curriculum, but they haven't is some of them, some bits of it, is that some nice stuff going on up in Seattle. And there's a little bit good stuff going on up in Boston, but I'll review some of that, and we talked to them. And we've been sharing resources and inclusion environment, a whole school policy, I think it's about parents should be thinking about this thing in a much more wider level than just their own child. I think, when you say whole school policy, then you know is bullying is disability. Part of the bullying policy is has that been recognized? What about cyber bullying? How are disabled people being treated in cyberspace as well. So all these things come around, I mean, huge, but I think what you have to do is just deal with what's in front of us, but then also work collectively to find the more inclusive environment. And then if you don't know enough about inclusion, please read about it. Because as we sometimes say, the road to hell is paved with good intentions, you really need to know what what this really means, what inclusion is and what it isn't.

Qudsiya Naqui:

Absolutely. And going back to something you were saying earlier, on one hand, it's really important that disabled people lead a lot of this work and are the ones designing these curricula, etc. However, non disabled people need to be active participants and that needs to start really young so that in the end, disabled people aren't constantly doing the work of having to fight for inclusion. If you have, say, a non disabled student who has been educated in this disability positive disability conscious environment, when they go to their workplace, when they go to their civic organizations in whatever they do, they'll be conscious. And they'll be part of the solution rather than part of the problem, right?

Alan Holdsworth:

Exactly, yeah. And I think that's really is like what you say, because I mean, at the end of the day, you these schools you leave without information or ignorance, we prefer them to leave with information about disabled people rather than ignorance. And I think that's like the biggest challenge. It's a big thing. So that's why I said if we cut the issue down. So what we're trying to do, right what we're doing like tomorrow, so while we're doing a professional development for teachers in the whole school district, so that will help them know what we're doing in terms of resources and what we can do to help you got to break it down into those those chunks and then think about in those ways. The other thing we've been doing is we took advantage of is when we didn't kind of target colleges, which have huge Teacher Education colleges. And then we got this huge teachers to teach the lessons. And that's another way of getting into schools where the student teacher goes into, hey, look, I got these lessons, you know, and they did other projects. So that's another successful thing we've done. We've done that with over 120 future teachers.

Qudsiya Naqui:

That is such an important point. And I'm really glad you brought that up what they need to know they can take that into their work as well. Well, this has been such a great conversation. Thank you so much, Alan for taking the time to speak with me.

Alan Holdsworth:

No problem. I loved it. Yeah, love to do it again.

Qudsiya Naqui:

Thanks for listening to this episode of down to the struts. This podcast would not be possible without the energy and creativity of Adrian Kong, Ilana Nevins and Avery Anapol. To learn more about the project and access resources from this and past episodes, visit our website at www.downtothestruts.com you can subscribe rate and review the podcast on Apple podcasts, Spotify, Stitcher, or wherever you love to listen. You can also follow us on Facebook, Twitter, and Instagram. Thanks as always for your support and looking forward to the next episode so we can get back down to it.