

Vince Diorio and Taylor Harris Interview Transcript

April 4, 2014

Introduction

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CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at info@storyminders.com with questions or topics and guests you want to hear on an upcoming show.

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CHERYL: Welcome to Stories from the brainreels for April, 2014. I've been talking a lot lately about maybe transitioning out of this show and focusing only on my call-in show on the [Brain Injury Radio Network](#). And yet, I keep meeting people whom I want to interview and present here. So here we are! I have two very exciting people to introduce you to today: Vince Diorio and Taylor Harris. Before I bring them on, though: local disability arts news.

Disability Art and Culture Project is seeking performers for our Disability Pride Art and Culture Festival 6, this May 16-24. And we extended our original deadline for submissions to April 11th. We are interested in working with and supporting performers from any marginalized community, whether you have a disability or not. Performances can be dance, poetry, prose, video, performance art, or just about anything that you can do in 8 minutes or less! Please read over the audition form found on the DACP website, www.DACPHome.org. Contact us with any questions at disabilityartculture@gmail.com or 503-238-0723. Performances are May 23rd and 24th, held in the accessible venue Zoomtopia, Studio 2. A small stipend will be offered for each performance piece selected. Download your audition form TODAY and return it to DACP by April 11, 2014!

Read more about the festival, and find the audition form at www.dacphome.org/2014/03/14/call-for-artists-festival-6/. And visit our Facebook page for posts and pictures about our work in the community with inclusion and furthering the artistic expression of people with both apparent and non-apparent disabilities: www.facebook.com/DisabilityArtandCultureProject

The first interview is a 10-minute conversation with Vince Diorio, founder of [The Creativity Expo](#), which is an arts exhibit in New Jersey where all the artists are people with brain injuries. Vince will tell you about his work and how the yearly exhibit runs. Next, I talk with Taylor Harris who is a speech-language pathology student with a disability. We talk about what we have in common with our disabilities as well as how she will go on to study and work in rehabilitation as someone with a disability pride perspective.

We also tell a lot of hilarious disability jokes at the end, all created by people with disabilities! Now to the two interviews.

Interview with Vince Diorio

VINCE: My name is Vincent Diorio. I do cognitive rehabilitation with a private company called NeuroRestorative. It used to be tied to The Mentor Network. I've been doing that for about 14 years. I work with individuals in their homes and in the community. The goal is to keep folks close to home.

CHERYL: You mean as opposed to like a nursing home or a facility, right?

VINCE: Correct. The goal is to keep folks as close to home as possible and to encourage growth and independence within the community.

CHERYL: Mmhmm.

VINCE: Most of the things I've been doing, as far as rehabilitation's concerned, is kinda some traditional approaches: paper and pencil exercises, computer-based cog work. But I've found that approach very limiting.

How The Creativity Expo got started

CHERYL: So I know one of the huge things that you're doing right now--all volunteer--is something called The Creativity Expo. And I would love to hear how you got interested in going from cognitive rehab to art exhibits.

VINCE: First, I know what art has done for me. I've always been associated with the arts in one way or another, visual arts, and found it enriching in times of trouble. Sometimes the arts seem to become a healing force for me. So through my work as a clinical coordinator/cognitive rehabilitation specialist, I run a volunteer group, a group consisting of brain injury survivors and their caregivers. Through that association, I found that there were a number of people in the group who had some arts background. And we decided at some point--this is going back 11 years--that we would put an art show on, just within the group. That expanded into The Creativity Expo itself. The idea was to start small, but actually what happened was I was able to secure a professional gallery space through my association with Raritan Valley Community College where I was an art student. So with all that space, I thought, well let's see if we can fill this up! I began to advertise, mostly through the newspapers and through the Brain Injury Association of New Jersey, which is now the [Brain Injury Alliance of New Jersey](#). So I was able to use their site and various other media outlets to reach the public and let them know this opportunity existed for anybody involved in the arts, anybody involved in the creative process, to present their work.

How the brain injury survivors respond to making art

CHERYL: So you talked about you were first interested because you know what art does for you. The survivors of brain injury who you work with, did they have the same response to making art?

VINCE: Well, I wanna differentiate between the survivors that I knew in my group who were artists before and the survivors who sort of got into the arts after their injury. There seemed to be two distinct

groups. I guess I identified with the folks who were artists. I could sort of understand how they wanted to have an opportunity to kind of get their feet back into the process again. The folks who kind of picked it up afterwards were more of a mystery to me. I noticed that many of the folks who've shown their work in my show and started the arts afterwards had just incredibly dynamic work. So I think I was very fortunate in that this group that I facilitate, it's existed for about 16 or 17 years. And there's just a core of people in there, survivors and family members who were very dedicated to the group process and wanted more. And so when I suggested that we think about putting this expo together on just a small level, everybody just jumped at it. And so we had poets, people who did prose, several visual artists. One young man worked for Fox when Fox was just starting, building their programming as the senior arts person at Fox. And he still does all the design work and advertising work for the Expo. Just a whole range of folks were involved in the arts. So it was very easy for me, that first show 11 years ago, to put together a pretty good show with about 11, 12 people. And it's grown quite a bit since then.

CHERYL: Yeah, based on the pictures just on your Facebook page it looks like it's way more than 11 or 12 artists by now.

VINCE: Yes, there's no lack of participation. It's a case of build it, and they will come.

CHERYL: Mmhmm.

VINCE: There's such a need for this kind of thing, this opportunity. My biggest job is to get the word out because I just know that there's a lot of people that aren't being reached because they're just not hearing the message. But they want to do this.

CHERYL: Mmhmm.

VINCE: And I get so much back from this and from the participants. The most sincere feelings of gratitude that I've ever experienced with other people has come through this process. And so, I think that's what keeps me going, is just to know how grateful people are for the opportunity be part of something dynamic as this Expo.

CHERYL: Absolutely.

VINCE: We're based in Jersey, but I'm close to Pennsylvania, close to New York. So we've been able to draw people in from states outside of Jersey. But primarily our participants are from Jersey.

How to get involved in the art show

CHERYL: Ok. So how could folks in your area get involved, either as artists in the next Expo or as volunteers. I assume you need volunteers.

VINCE: I can always use a few. The hardest part is the set up and making sure the gallery is secure during the 10 days that the show is open. So I primarily need people to gallery-sit and to help with some of the preliminary organization of the show. Hanging, I can always use a few good hangers. That's an art in itself. We can always use some volunteers, yeah.

CHERYL: Great. Are you sending out a call for artists to be in this year's Expo?

VINCE: That call will go out within the next week, no later than the beginning of next week.

CHERYL: Ok. And when is the Expo?

VINCE: The Expo is July 12th. That would be the opening. And then, it would go to the 22nd, I believe. You know, people want this now. It's kind of like it was a more casual event for me at one point. But now, it's expected, which is fine because I get very focused and stimulated by this event myself. I look forward to it. I look forward to putting it together.

CHERYL: It sounds wonderful. You know, I was only able to pull off an art exhibit once. And that was last year. I curated a show here. And we had several musicians and a lot of visual artists, all people with brain injuries. And boy! I just don't even think I would ever try that again. So kudos to you for having this go on for 11 years. It looks wonderful online. It sounds great. Your reasons for doing it are great.

VINCE: Thank you, Cheryl. I appreciate that.

CHERYL: Yeah.

VINCE: I just wanted to mention that there are no restrictions. Everybody who wants to enter will have a place at the Expo. That's a promise. Nothing is rejected, as long as it's lawful. So we'll find a place for whatever people want to present. We can have everything from a classical masterpiece to a birdhouse. We'll find a place for whatever it is. We encourage all the arts and all the craft mediums as well.

CHERYL: Oh, wonderful.

VINCE: We also encourage everybody to think about a portfolio. If they have one, then we'll include it. You're also welcome to sell your work, and all profits go to the artist.

CHERYL: Oh, wow! Do all the artists have to be a person with some kind of brain injury?

VINCE: It's traumatic or acquired brain injury. That's the pre-requisite at this point.

CHERYL: There's something really important about holding events that are specific to a specific group of people and say, "this is your space where you can do this." But then, since it's open to the community for 10 days, it's not like it's a segregated event. You don't have to have a brain injury to go to the show.

VINCE: No, no [both laugh].

CHERYL: Are there any other things about your work or about the Expo?

The artists with brain injury are treated as artists

VINCE: There's nothing obvious, nothing tells you all these artists have a brain injury. As a patron, as somebody walking in, you're going to have to pick up the literature to figure that out. Because there will be nothing that will indicate that. People walk in all the time and look at the whole show, and

sometimes they don't even realize that the participants have brain injuries. That happens all the time. If you don't pick up the literature, you will not necessarily know. That's interested me.

CHERYL: It's unusual. Most people have it very prominently displayed that these are artists with disabilities or artists with brain injuries. Can you talk about your choice to make it be sort of subtle? If you find the information you find it. If you don't, you don't.

VINCE: It wasn't a conscious. I just realized that when we started advertising that it was not a prominent part of how we presented the show. The way we put the show together was it's more in line with any professionally curated show. And it is professionally curated in terms of the arrangements, the choices that are made, how the work is displayed. It's all done in as close to a professional manner as possible. I think the fact that the work is done by survivors is important. But it's not the most important. It doesn't have to be thrown out there. I guess it's more of a personal thing. The bottom line is that this is about the creative process and how powerful it is, and how attractive it is, and in many cases, how healing it can be.

CHERYL: I just so appreciate your time. Thank you so much!

VINCE: Thank you very much.

Interview with Taylor Harris

CHERYL: Hello, Taylor.

TAYLOR: Hello.

CHERYL: Thank you so much for being on my show today.

TAYLOR: Of course.

To make a plan or not to make a plan

CHERYL: So I invited you to be on this radio show with absolutely no plan. This is a first for me. You and I had no plan, and generally that's just a terrible idea for me. Does that work for you?

TAYLOR: I was talking to a friend about this last night. And I said I'm going to be interviewed about ADD, I guess. And she said, "Oh, what's your plan? What are you going to do?" And I said, "Well, ADD doesn't really work that way. So I'm gonna wing it. And I'm going to be as genuine as possible" [laughs].

CHERYL: Is it better for you that we didn't make a plan?

TAYLOR: Maybe?

CHERYL: OK.

TAYLOR: We'll see. So I waffle back and forth on no plan versus every minute planned out. Sometimes it works out really well for me to have my day planned out to the minute. And some days that stresses me out.

CHERYL: Yeah, do you know which day it's gonna be, what kind of day?

TAYLOR: No. I make a plan, and sometimes I follow it. And sometimes it just poof.

CHERYL: And are you really that easy-going about it as you seem right now?

TAYLOR: No [laughs]. No, not at all. No, I have a lot of anxiety about it, actually. And it's fine. I deal with it. Sometimes I have panic attacks, but they're very few and far between. And I don't know if the anxiety is a symptom of the ADD or if it's a co-morbid thing or what. But I've never really not lived under the ADD label. So I don't know what is the disorder and what is not and what is me.

Would you get rid of your disability if you could?

CHERYL: I've heard people in other places ask the question, "If you could get rid of your disability, would you?"

TAYLOR: Mm, I don't think I would. I really don't think I would. I think that sometimes it's a lot of fun, and sometimes it is really frustrating. But sometimes it's more of--I hate the word gift. But it kind of is. I'm able to hyper focus on a lot of things. I'm not able to focus on a lot of things. But when I can hyper focus, I get jobs done. I'm really good at them.

CHERYL: I feel like for some people who say "yes, I would get rid of my disability," that tends to be--I think--people who have a more clear line: this is me, and that over there is the disability.

TAYLOR: Mmhmm.

CHERYL: But the way you described it, there's all this intertwining, and in the end does it really matter? Cuz it's all you, right?

TAYLOR: Yeah. If I got rid of my ADD, I wouldn't be who I am cuz it's such an intrinsic part of me. And I like who I am. I don't wanna be a different person.

CHERYL: One of the really neat things I've found in talking to you is that I really hear a lot of overlap in the way you describe what's challenging for you, what you like about yourself, and I think there was a third item in the list, but I don't remember what it was. Which, you may also relate to as well.

TAYLOR: [laughs] Yes.

What we have in common across disabilities

CHERYL: So I'm very intrigued by thinking about what things people have in common rather than separating people out and ranking them. Do you feel like, I don't know, someone with a brain injury and someone with ADD. Wait, let me back up. Is the appropriate thing to say, "someone with ADD?"

TAYLOR: I don't really--

CHERYL: What do you like?

TAYLOR: I was thinking about that on the way here. I hate it when people say, "I'm so ADD" because you can't be a disorder. It drives me insane. But how would I describe myself disability first? I was thinking, am I an "attention-deficient person?" That's weird and awkward. So I've always said "someone with ADD" or "I have ADD."

CHERYL: Ok, good. I just wanted to check. Do you see yourself as a person with ADD having things in common with people with other disabilities or other impairments?

TAYLOR: Oh yeah, yeah, absolutely. Lack of focus, impulsivity, hyper-focusing. I think there is definitely a lot of overlap. And from what you've told me about having a brain injury. I think when you were telling me different stories or different characteristics, I was like that sounds a lot like me! Oh [laughs]!

CHERYL: So that's like our common experiences of our impairments day to day. But what about the other parts of life, like how people respond to you?

TAYLOR: A lot of people are surprised when I tell them I have ADD, which is really weird for me. I actually had a professor tell me once--in a pottery class, so of course I was hyper-focusing cuz I was really into it. I had a professor tell me, "No! You don't have ADD. No way. You can focus. You're not hyper at all." It was so frustrating, and it was really insulting. There's so many different facets to this disorder. I tell some of my friends I have ADD, and some of them say, "Wow, yeah. That explains a lot." And some of them say, "Really? That's weird." And I don't know if they really change their interactions with me. I'm not very sensitive to that, I guess [laughs]. I don't pick up on it.

CHERYL: Talk about common experiences. If I had a dime for every person who told me I didn't have a brain injury, I would have so many dimes. I would just be swimming in dimes. There's a classic brain-injured person trying to make an interesting metaphor: I'd have so many dimes, I'd be swimming in dimes. I think most people would say something like "If I had a dime for every time someone said that, I'd own a mansion!" No, not me. I would just have a lot of dimes.

We met this person the other day. Lavaun and I are sitting there talking, and we keep saying the word "disability." We're at this restaurant; he's two tables over. He's like, "Did you say disabilities? I have a disability!" And Lavaun and I are both like, "Thank you for coming in our conversation. This is totally great." He said we don't look like we have disabilities. And I said, "Well, you don't either." And he was like, "Yeah." And I said, "So maybe we do look like we have disabilities because we are people with disabilities! So this is what we look like!"

CHERYL: We may be off topic. Well, you can't be off topic if you didn't have a topic.

TAYLOR: Off Topic: ADD and How It Has Affected My Life. Or like Off Topic: The Story of My Life. That'd be a great book title or a blog title.

CHERYL: It would. I can totally see that. Do you blog or write?

TAYLOR: I did for a little bit, but then I dropped it. That's another thing: I pick up projects thinking I'm going to devote so much of every day to this. I'm going to do this for years. And then I find something else, and I leave it. All the time.

Micro-aggressions and considering disability inferior

CHERYL: Now, what would you say to someone--I get this a lot, so I'm just gonna say it. "Oh, well I do that too, and I don't have ADD." Do people do that to you?

TAYLOR: Yes. Yes, they do. "I have trouble concentrating too. I don't think you have ADD." Again, it's insulting. But I tend to say to people, "Well, does it impact your life in a way that makes you unable to function in a way that's acceptable to society? Does it impact your life to the point that you find yourself in tears?"

CHERYL: I think that people say things like "You don't have ADD. You don't have a brain injury," I think they are trying to give a compliment.

TAYLOR: Yeah, I think so too.

CHERYL: Yeah, the problem is, you and I don't see ourselves as inferior to someone without ADD or a brain injury or anything that you wanna call it. And I was recently told it's a good thing that I look so close to "normal." I don't find that to be a compliment. I want us to get away from the idea that what's in the normal range is inherently desirable.

TAYLOR: Yes.

CHERYL: Yeah, let's just expand it.

TAYLOR: Why does it have to be considered different and strange and undesirable?

CHERYL: And I'll tell you what, it is very, very non-culturally sensitive. But we act like it's this completely universal thing.

TAYLOR: There's such a range of ability regardless of a person's diagnosis or label, that it seems silly not to accept it. And it seems close-minded.

CHERYL: I think it's very close-minded. As soon as there's the label or the perception of a disability, people automatically assume well, you couldn't be valuable. You can't contribute. So you're on the low end, you're on the throwaway end. And I think that disability and impairments are so tied to capitalism in this community, and that's why we don't like, and we think disability is bad. Because we think you're just gonna get on benefits and not give back, and you're gonna be selfish. First of all, we're all different. Second of all, I know plenty of people who don't have a disability who are moochers.

TAYLOR: Oh yeah.

CHERYL: Why do we get the bad rap? Tell me. Why do we get the bad rap? I will give you a dime if you can tell me why we get the bad rap [both laugh].

TAYLOR: I wish I could earn that dime [laughs].

CHERYL: Well, you have a disability, so you can't. That's why [both laugh]. If you didn't have a disability, you'd be earning buckets of dimes all the time.

TAYLOR: I'm sure.

CHERYL: Yeah, I hear that's what non-disabled life is like.

TAYLOR: Just throw money.

CHERYL: People just leave the house, and money just comes to them just by virtue of being non-disabled. And white and straight.

TAYLOR: Mhmm.

CHERYL: Male helps.

TAYLOR: Yes.

Studying speech-language pathology with an affirmative disability identity

CHERYL: I want you to talk a little bit about what you're studying right now because you seem like a person who has a very affirmative disability identity.

TAYLOR: Thank you [giggles].

CHERYL: Yes! You don't have shame about the fact that you've got ADD. You feel pride. You are perfectly satisfied to say, "I need this accommodation."

TAYLOR: I tell you, it has taken a good 20+ years to get to this point though. I was diagnosed when I was seven, and I started medication when I was eight. And let me tell you, Ritalin is the devil, at least the formula that they used then. And I've been realizing over the past few months, I have a lot of holes in my memory. I don't know if it's just because I was a kid or because I was on medication. And that confusion scares me. I really don't know how to feel about that. I've been on other medications. Caffeine does nothing for me. Actually, caffeine has more of a leveling effect than anything else. A lot of my friends say, "I need a buzz. I need caffeine. I need to wake up." But that's really weird to me.

CHERYL: Is that because you're already feeling buzzy or because the caffeine calms your system down?

TAYLOR: That's a really good question. Or because I've developed such a ridiculous tolerance to stimulants. I don't know.

CHERYL: Oh, that's right. Because you were put on speed as a child by the doctors.

TAYLOR: Yes, yes I was. My mom actually fought it for a really long time. My mom didn't want to medicate me. She cut sugar out of my diet. She cut refined flours. There were a bunch of other things she did that I don't remember cuz I may have been too young. But eventually, it was just the medication.

That was the only thing that worked when I was a kid. And I've had 20 years to develop some coping mechanisms, so I know what works now. I still have issues. I feel that having a disability and identifying as someone with a disability has really given me some incredible empathy, and I plan to take that into speech-language pathology.

CHERYL: Yeah, yeah, and thank goodness for the clients you're gonna see.

TAYLOR: I hope so.

CHERYL: Yeah. I could not go back to the field of speech pathology. I'm a lot improved now, skills wise, but I still would have a lot of trouble staying enough steps ahead of a person, say, with a brain injury to actually do good speech therapy. We could hang out and be buddies, but in terms of staying on top of what needs to be done in therapy, I'm still not fully there. But the real reason I didn't go into the field, aside from the fact that I have to go to sleep every 4 or 5 hours, is that I didn't feel like I could have integrity and have an affirmative disability identity and be a rehab clinician.

TAYLOR: Mmhmm.

CHERYL: So you're studying speech pathology. You're about to go to graduate school.

TAYLOR: Yes!

CHERYL: How do you do it?

TAYLOR: I don't know [laughs]. How do I do it? I don't know. How do I face the daunting prospect of grad school?

CHERYL: No, not even that part.

TAYLOR: Or how do I go into rehabilitation and therapy with a disability-positive identity as someone who is treating people and trying to help them "overcome their struggles"?

CHERYL: That's the question. Yeah.

TAYLOR: I want to go into it with an outlook of you're ok the way you are. The approach that I wanna take is mostly that I just wanna be there for it. I want to be there. I know that there are people who don't like the way that they speak or don't like the image that they project, which is why I really want to work with transgender population. I have an image of myself that I would like other people to see and interact with and relate to. I know that that's not always the person that I project. I have a disability-positive identity, but at the same time sometimes I really don't like it. It's not that I wish I didn't have ADD, but sometimes I just hate these parts of myself. And then I get over it. I'm like actually, it's not so bad. But I mostly just want to be there. I want people to realize--not oh, today I realized, but--to realize a goal of who they want to be. So I know that I have this image I'd like to project. I'm guessing that other people have the same feeling. There's a person inside of me that doesn't match up with who's on the outside. And I want to bring that inside person out. I want to help people realize their, I don't know how to say it.

CHERYL: No, it would be very hard to come up with one word what: their selves, their expressions. I think it's probably a lot of words. I think the key is that you wanna help them realize whatever it is they're trying to realize.

TAYLOR: Yes!

CHERYL: Which is why you can't come up with one word for it.

TAYLOR: Exactly!

CHERYL: Cuz it's their choice and their life. So you're referring not just to someone who's transgender but maybe somebody who's got a communication disorder, right?

TAYLOR: Yes.

CHERYL: So one thing that I encountered when I was in graduate school was sometimes people felt sorry for their clients.

TAYLOR: I hate that.

CHERYL: I hate it too.

TAYLOR: [sighs] You feel sorry for people who are less than, but no one is really less than.

CHERYL: I agree. I think that society decides--or societies decide--who is superior, who is normal or average, and who is inferior. It can't possibly be pre-determined part of humanity.

TAYLOR: Mmhmm. You have a quality that is worth pitying. You are pitiful. And that is so terrible and so wrong. Everyone lives with a complication. Everyone has it hard sometimes, and it's ok. It's ok to have it hard, and it's ok to say, "I'm struggling."

Were you ever shy about your ADD?

CHERYL: Did you used to be shy about the fact that you have ADD?

TAYLOR: Well, yes and no. From what I remember, I used to say, "Oh, I have ADD, but I'm this other person." It was separate from me. And I didn't embrace it. It is part of me. It shaped who I am. Another thing. My confidence in myself and in just going with it has shot through the roof since I started embracing that I have ADD. I have attention deficit disorder, but at the same time, it's not just attention. I have started calling it executive functioning disorder because it affects so many other things. In one of my speech and hearing sciences classes, we started going through executive functioning as it relates to language and language development and child development. And I went, "I'm impaired there and there and there and there and there!" And oh, I have an executive functioning disorder! I don't have attention deficit. It's so much more encompassing. It's much broader disability than just attention, and people don't understand that.

CHERYL: I'm sure you get, "Well, why don't you just pay attention?" I'm sure you get that advice, right?

TAYLOR: All the time.

CHERYL: You can certainly do that for short periods of time. Ok, now I will do such-and-such. But that doesn't mean you're gonna do it right, still. That doesn't mean it's not gonna cost a lot.

TAYLOR: So I quit feeling like I had something to hide or that there was a part of me that I didn't want to embrace. For a long time, I felt like I'd just get over it. But then somewhere around my going back to school, I started to realize that this is actually a significant part of myself. And I quit hiding from it, and I said you know what? I do have ADD. And I'm gonna try to figure out how to make it work for me. The first thing I do on college campuses now is hook myself up with disability support. I'm able to go in and say, "These are the accommodations that work for me. How can I get those?" It's become a pretty painless process. Once you start asking for help, it's so much easier to ask for help again. I actually really like it because I've started connecting with people I wouldn't normally connect with. Like you. And the director of the disability support services at PSU is just one of the most wonderful people I have ever met. She's fantastic. And she's been encouraging and completely supportive and everything.

CHERYL: So would you call yourself a self-advocate?

TAYLOR: Absolutely. Yes. My mom was my advocate for a really, really long time. But then when I went to college, she didn't really have the time to ferret out all these avenues of support for me. So I've had to do it myself, and I've become pretty good at it.

TAYLOR: One of the most profound things anyone has ever said to me regarding ADD was, I was about 17 or 18. My best friend--I said something about, "Oh, well, I have ADD. I can't...whatever." And she said, "It's not a crutch." And just those four words. Sometimes I get really down on myself. I have ADD, and this is hard for me. And then I think, yeah, but it's not a crutch. I can't use it as an excuse, and I can't lean on it as a reason to say, "I can't do that."

CHERYL: What's interesting is that you talked about your self-confidence growing when you embraced that you have a disability. And that's so intriguing because most non-disabled people feel like how could you have any confidence unless you were normal or cured?

TAYLOR: Right.

CHERYL: But in fact, when it is your reality, and you embrace it instead of fighting it, you're so freed to move forward. And maybe that means that sometimes you actually can't do something in the way that you tried.

TAYLOR: Mmhmm.

Coping mechanisms and strategies

CHERYL: So like, you talked about you get coping mechanisms, you learn a strategy. Or you sorta mess it up and try it again another time.

TAYLOR: You know what's been a really, really awesome technique for me, or a really awesome tool? Is all the smart phone stuff.

CHERYL: Yes!

TAYLOR: That calendar and setting alerts. Technology is amazing, and it is an amazing tool for people with disabilities.

CHERYL: Oh yeah. Especially the Apple products. I am a fan of the many accessibility features that they have. And yeah, with executive function, those quick, one-touch, it's all there sort of color-coded, it's organized. That stuff is great for executive dysfunction.

Do you know what this is? Just take a guess.

TAYLOR: A square of yellow paper?

CHERYL: Yes, it is a square of yellow paper. It is cardstock. So it's a yellow card. Are you familiar with soccer?

TAYLOR: Yes.

CHERYL: This is the yellow card. Often, we just say, "yellow card." We don't hold it up anymore cuz when Andy says, "yellow card," I know I'm getting the yellow card. Sometimes when we're in a problem, I sort of spiral out of control emotionally. And the more you try to explain, the more words that come in, the more shut down I feel. And then I start to get confused. And then I start to yell, and then I just make it worse and worse and worse by yelling and crying and getting defensive and not really recognizing, you know what? Let's simplify this and spell out the problem. And so when that happens, I get the yellow card. And the way the yellow card works here is both teams have to shut up. So I need to stop being defensive, yelling, blaming. But Andy also has to stop explaining and trying to fix. What I like about this technique is having this yellow card depersonalizes it. It's not about you're being a jerk, you're being too sensitive, you're being too defensive. There's the agreement that there's nothing personal.

TAYLOR: Mmhmm.

CHERYL: It's simply about this conversation is out of control and is not moving in a productive direction. So everybody, time out. But because we both have to take a time out, it's nobody's fault. Even if I know I'm the one who's causing most of the problem. Yellow card! And we're done. And then there's time to calm down and then problem-solve. You're nodding very knowingly, like you can relate to the description I gave.

TAYLOR: I'm nodding like I might need to start implementing this in my own life. I have a tendency to spiral emotionally and get worked up. And sometimes, I'm able to recognize I'm not reacting to this situation very well at all, and my reaction is making it worse, and I need to step away. Sometimes I don't feel like I'm the one who needs to step away. So I think that completely depersonalizing it and making it about the conversation and the situation is a really good idea for me.

CHERYL: Yeah, because in the end maybe you or maybe I are the ones who are misunderstanding and are spiraling out of control. But does it do any good to just blame us or blame yourself? That's not productive.

TAYLOR: I don't think it does any good to blame anybody, regardless of whose fault it is.

CHERYL: Right. And what are you gonna learn from feeling ashamed at how you spiraled out of control? This little external cue, this yellow card, no offense. Well, actually, it is. It's for committing an offense [both laugh]!

TAYLOR: It is an offense!

CHERYL: No offense, but let's take a break. Anything you can do to get on with good communication. Until one day we're just fixed, and we don't have this problem anymore, right [both giggle]?

TAYLOR: Well, who says it's a problem to begin with? It's just a difference.

Improving versus treatment, rehab, or fixing someone

CHERYL: So that leads me, though, to a question. For me, some of the stuff I do in my behavior, my communication, is problematic. And I would like to be better at things. But I don't want to work on them in a way that is fixing or curing. I don't like the instance that we should be going to rehab and always improving because I don't hear that requirement to improve put on anyone without a diagnosis.

TAYLOR: Mmhmm. I'm trying to figure out how to put into words what I'm, what I'd like to respond [giggles]. That's another thing. I have a very hard time composing my thoughts into words.

CHERYL: Well, and especially cuz now we're getting really vague and abstract.

TAYLOR: Yeah. I used to go to counseling. And I think everyone can go to counseling, and it's not something to be ashamed of or something to be embarrassed about. I think that self improvement, regardless of your level of ability or disability, is always a positive thing. But I don't think that calling it "rehab" or "treatment" is a positive thing. I think that those two words and other words like them have very negative connotation. And they build up resentment, which is poisonous.

CHERYL: Mmhmm. Well said. Did you end up saying what you were hoping you would say?

TAYLOR: I think so [laughs].

Dealing with getting stressed and self-soothing techniques

TAYLOR: I get stressed out over what seems like practically what seems like the most trivial things. But in the moment, I can't get out of it. And I can't remove myself from that stress and from the anxiety and the panic. And then I just dissolve into tears. And then, once I get that out, it's ok, and I'm fine. I know that I'm going to be fine. I just need to cry. And then after I have cried, and after I've let it out, I find a solution. I don't know. Maybe it's just the mounting stress needs an outlet, and then it'll all be ok.

CHERYL: Yeah, yeah.

TAYLOR: Sometimes when I'm spiraling out of control, I just need to be hugged, I need to be compressed. It's very centering.

CHERYL: Yeah, yeah. I've definitely been known to pile the pillows on, get under the pillows. And I feel cocooned. I've certainly gotten weird stares about that cuz those are common practices to do with autistic kids: deep pressure, sitting on a pile of pillows on top of the kid and hugging.

TAYLOR: And Temple Grandin's hug box.

CHERYL: Yes, her squeeze machine, yeah! And so I've certainly had the doubters look at me like, "Well, you're not autistic. Why do you need that?" It's not about your diagnostic label. It's about neurologically and emotionally, this feels really good, this is a productive self-soothing thing to do. Would you rather I keep crying?

TAYLOR: Mhmm.

CHERYL: Or would you rather I help myself?

TAYLOR: Right. This technique doesn't belong to another disorder. If it works, anyone can use it.

CHERYL: Yeah, and people shouldn't be shamed or belittled for it.

TAYLOR: No.

CHERYL: It doesn't have to be startling. And just like I would like disability to be considered normal-- because it is normal--why can't somebody squeeze themselves or rock for a little bit to clear their head?

TAYLOR: Mhmm.

The Loud Hands Project, how disability isn't always negative, and on not being inspiring

CHERYL: This is no big. Have you heard of [The Loud Hands Project](#)?

TAYLOR: No, I don't think so.

CHERYL: You know the term "quiet hands."

TAYLOR: Mhmm.

CHERYL: Ok, so The Loud Hands Project, they put together a book called "Loud Hands: Autistic People Speaking." And it's all essays, blog posts, or transcripts of speeches all by autistic people. The idea, of course, is don't tell me to quiet my hands. My loud hands moving means something to me and works for me. And when you tell me that you think I should stop because you don't like it--

TAYLOR: Cuz it doesn't fit into your box.

CHERYL: Right. But what if you were to expand and not be disturbed by it. It's a brilliant book. I think this book is gonna be read primarily by people who are already in the autistic community or are allies. I would like it to be read by the larger public because we often criticize autistic people for how rigid they are. But who's being rigid? When you tell an autistic person, "Put your hands down. Quiet hands. Stop spinning. Don't do it that way. This is not how we do it." Well, you're also being a bit rigid there. Stop asking one side to be flexible if you're not also going to be flexible.

TAYLOR: Right. Give and take. It's not fair. Not that anything is fair, necessarily. But it's not fair to ask someone to change if you're not willing to change yourself or expand your mind and your notion of what is acceptable and what is not.

CHERYL: And I think what's not ok is to assume that someone is always struggling.

TAYLOR: Right!

CHERYL: Like, you hear the term "disability," and you just assume people are always struggling. But you've already talked about things that work well for you in having ADD.

TAYLOR: Mmhmm.

CHERYL: And you are who you are, and you wouldn't change yourself, so therefore it can't be all negative and all struggling.

TAYLOR: Right. I have a frustration along the lines of "Oh, you're so inspirational." So I was a caregiver for a long time, which is how I got into speech-language pathology. And actually, that's part of how I developed such a positive identity regarding my ADD. So when I was a caregiver, I worked with a little girl who sustained a TBI when she was 18 months old. And I worked with another little boy who had a stroke in utero. He's legally blind, and he's got cerebral palsy, and he's got an auto immune disorder. And he's so funny. He likes disability jokes [laughs]! He has epilepsy, and he loves to tell seizure jokes and blind jokes.

CHERYL: I would love to hear his jokes!

TAYLOR: I'd tell you all of his jokes. He loves anything to do with getting from A to B. He loves public transportation. So we'd come into Portland, and we'd ride the MAX. The thing that drove me insane was how many people would come up and say, "Is he Ok?" and not look at him, not interact with him at all. Or ask me, "Why is he in a wheelchair?" And I'd say, "Ask him yourself. He'll tell you."

CHERYL: Nice!

TAYLOR: And he would. He'd tell you absolutely everything. "My legs are wobbly. They're not strong. I can't see very well," stuff like that. Then, after they listened to him with this look of oh you poor, poor angel on their faces and mostly looking at me because they don't know how to interact with him, they'd look at me and say, "Oh, bless you." [laughs] Really!? Bless me? Why? Why bless me? And why bless

him? He's just living his life, and sometimes it's harder for him than it is for you. So I'm here to help him with that. And that's it.

CHERYL: That's it.

TAYLOR: And that's the end of the story.

CHERYL: And it's again, people think they're giving a compliment, but it is so dehumanizing to tell you that you're a saint and to tell him that he's an angel.

TAYLOR: It really is. Mmhmm. We were walking down the street one time , and this group of guys who were about, they must have been like 20, came up to us. And they said, "Ma'am, do you mind if we pray for your son?" Personally, two things. I'm not a ma'am [laughs]. And he's not my son. He looks like he could be my kid or at least my little brother. We look similar enough. And people would say all the time, "Oh, your son blah blah blah." "It's not my kid."

CHERYL: You shoulda said, "It's my boyfriend."

TAYLOR: Right [laughs]. I should have!

CHERYL: There's a lot of assumptions, a lot of normative assumptions like that.

TAYLOR: I was kicking myself after these boys came up to us and said, "Do you mind if we pray for your son?" And I said, "Ask him. He's not my son. Ask him if he's ok with you praying for him." And so they said, "Are you ok with us praying for you? Do you mind if we pray?" And he said, "Uh, yeah?" And so they bent down in front of him. One of them put his hand on his knee and said, "Lord, please bless this boy and help heal him and make walk again!" Make him normal, right? Basically. And I was so mad at myself that I didn't tell him to stand up and start walking, cuz he can [both laugh].

CHERYL: That's not what I thought you were gonna say! "Come on. Let's go ahead and try walking!"

TAYLOR: "Ok, try standing up!" They would have just died [laughs]!

CHERYL: I thought you were kicking yourself for not telling them to go away.

TAYLOR: Oh no!

CHERYL: No, you! Oh!

TAYLOR: I'm kicking myself for not having more fun with it.

CHERYL: I also wish you had had more fun with that guy, and he'd gotten up and walked. Cuz that would have been hilarious.

TAYLOR: And he's really unsteady when he walks too. So it would have been like--

CHERYL: I'm just learning! I'm just learning!

Lack of privacy and respect around disability

TAYLOR: I've never done this before [laughs]! Are you familiar with [Maysoon Zayid](#)?

CHERYL: Oh!

TAYLOR: [laughs] I just found her TED Talk.

CHERYL: You know, I like that less than I like her stand up. She gets a little inspirational in the TED Talk, and she probably had to. But when you just watch her plain old stand up. And some of the lines were from her stand up, like "I got 99 problems, and palsy is only one of them."

TAYLOR: Mmhmm. "No, I'm not drunk, but the doctor who delivered me was."

CHERYL: Yes.

TAYLOR: I love that.

CHERYL: I love Maysoon, mmhmm.

TAYLOR: I watched an interview with her on the Australian equivalent of Good Morning, America or something like that. The way these Australian interviewers just talked down to her, and she just took it. They pried. They pried into her life, and the way that they thought they could ask these questions. People feel entitled to information about your personal life.

CHERYL: Uh-huh.

TAYLOR: Yeah.

CHERYL: When somebody approaches you and asks you all these personal questions about your disability or your life, and you protest, so often they'll say, "Well, you have the right to not answer." They're deflecting the responsibility off from themselves. Yes, you have the right to not answer. But people also do have a responsibility to try to communicate respectfully. And if I ask you an intrusive question, and you say, "Well, I'm not gonna answer that," then you look like the jerk. When in reality, they don't wanna admit that they may have asked an inappropriate or rude question.

TAYLOR: Mmhmm.

CHERYL: When someone perceives that you have a disability, it is very dehumanizing to then demand personal details.

TAYLOR: Yeah.

CHERYL: And I don't go up to people based on something about the way they look and ask them a painful question.

TAYLOR: Mmhmm.

CHERYL: Yet, that's what happens once you're perceived to have a disability, whether someone sees it in something about your body, or they find out about it. I don't know why they start asking personal questions with no offer to tell you something.

TAYLOR: Mmhmm.

CHERYL: Do people ever say to you, "Oh, I know someone with ADD!"

TAYLOR: Not really, because a lot of people my age know someone--

CHERYL: Oh, that's right.

TAYLOR: --know a lot of people with ADD. A couple years after I was diagnosed, there was what I like to call the diagnostic epidemic. Everyone wanted to medicate their hyperactive child. Kids have a lot of energy. Come on. But not everyone who was put on medication has attention deficit. It really, really bothers me.

CHERYL: Yeah.

TAYLOR: There're a lot of people who say, "I **had** ADD." That kills me. "I had ADD when I was younger." Ok, so what are you saying, that I should've grown out of it by now?

CHERYL: That is what they're saying.

TAYLOR: Yeah, it is.

CHERYL: I overcame it. Why didn't you? Maybe you didn't have ADD then.

TAYLOR: Right, or maybe you didn't overcome it, you just don't recognize that all of the coping mechanisms you put in place work so well that it doesn't impact your life anymore in the same way it impacts mine.

CHERYL: Good point. Maybe you still do have it, but don't shame me for still having struggles with or for still working on it.

TAYLOR: One of my favorite things to say lately, not even related to disability at all, is--and just to be funny and to be a jerk is--"You don't know my life." But I feel like it totally applies. You don't know my life! So don't tell me how I should have been living it or how I should go on living it. That is a ridiculous standard for you to hold me to.

CHERYL: That's brilliant. This is the one I get if I say I had a brain injury: "Oh, was it traumatic?!" Ok, so if it was, I might re-traumatize myself by telling you about it.

TAYLOR: Right.

CHERYL: And then the other one that I get is, "Oh! I know this girl who was hit by a car, and she was in a coma." I'm like, ok. So the tears are starting to come up, and I'm the one who's gonna look like a fool

when I start crying. Or I'm gonna bottle my emotions up, and they're gonna come out in the form of me lashing out or just having trouble doing what I'm doing because I don't wanna look like a fool and cry in public. But you're the one--knowing that I had a traumatic brain injury--and now you are telling me, without my permission, telling me the story of someone else with a brain injury. That triggers me.

TAYLOR: Yeah. I think that people are trying to relate to what is strange to them. That's part of the human experience. We want to relate to people. We want to find some commonalities, but if you can't find--Find something else you have in common!

CHERYL: Thank you! There's something particular about disability around that because--What's your ethnicity? Do you mind?

TAYLOR: White.

CHERYL: So your ethnicity is white. My ethnicity, also, I'm white. I am olive-complected with brown hair, but I'm white. Regardless of times when I'm tan and people mistake me for not being white, I still have all the white privilege. I don't know anyone--and I wonder if you know anyone--who shares our ethnicity who would go up to a black person and say, "I totally know what it's like to be discriminated based on race! Cuz one time, I went to this place...." I don't know anyone who would do that!

TAYLOR: Mm-mm, nope.

CHERYL: Yet, you can go up to someone and be like, "Oh! I had bunion surgery, and I was in a wheelchair for three weeks, too. And I know exactly what it's like to be in a wheelchair."

TAYLOR: Mmhmm.

CHERYL: For some reason, when it comes to disability, people are always trying to relate. And whether it's to tell a traumatizing story about someone else you know. It doesn't work with ethnicity. It doesn't work with class. Why do people think that works with disability?

TAYLOR: It doesn't work with gender, either.

CHERYL: Gender, sexual orientation.

TAYLOR: Mmhmm.

CHERYL: Why do they do that to us?

TAYLOR: I don't know. I wish I did because then I could figure out a response. Well, I could figure out a retort [giggles].

CHERYL: A retort would be most excellent. Well, your other retort, "You don't know my life."

TAYLOR: Yeah, you don't know my life!

CHERYL: That's hilarious.

TAYLOR: I don't have an answer for this.

CHERYL: Yeah.

TAYLOR: I do things the way I do because of who I am, and I don't need to have an answer. You don't know my life.

CHERYL: You don't need to have an answer. Why do people keep asking these questions?

TAYLOR: That is a great question in itself.

CHERYL: Yeah! Quit it!

TAYLOR: I can tolerate things for a while, and then all of a sudden it just [crack].

CHERYL: I know that feeling.

TAYLOR: We don't have this in common. So let's find something else.

CHERYL: Yeah. So how come when I tell you I have a brain injury, you have to say like, "Oh, I think I might have a brain injury too, cuz I forget names." Why did you do that?

TAYLOR: Yeah.

Disabled people as teachers and inspirational

CHERYL: Disability, historically, is not in the conversation yet in terms of this is a positive diversity factor, that disability or ranges of disabilities, ranges of abilities, enrich society. It's still seen as impediment, it's negative, you can't contribute, you're gonna suck resources and give nothing back. We're still stuck in that. I would like to see the disability community not be stuck in the role of teachers.

TAYLOR: Inspirations.

CHERYL: Inspirations. And we are just here to educate you about what--Certainly my population of people with brain injury, we're often told to learn to think for ourselves, learn to problem solve. And yet, when it comes to questions of how should I communicate with a person with a brain injury disability, people come to me, "What do I do?" I don't know. Think for yourself? I mean, I would like to hold your hand in this, but I kind of am busy right now with my life and my stuff. So, as a non-disabled person, can you try to strive for the independence that you demand from us?

TAYLOR: Right.

CHERYL: Oh, you said something earlier about don't ask someone to change unless you'd be willing to change yourself. Don't ask me to think for myself if you're not gonna think for yourself.

TAYLOR: Mmhmm.

CHERYL: We need to have some equity in our standards if we're ever gonna have equity.

TAYLOR: Right.

Wrapping up with disability jokes

CHERYL: Well, this conversation has been a downer, start to finish, Taylor! So if you could leave us on a high note, that would be great.

TAYLOR: Oh, I would love to. I do have some ADD-related jokes. How many ADD kids does it take to change a light bulb? Let's go ride bikes [both laugh]. That's the only one I have, actually.

CHERYL: Can I add that to my collection?

TAYLOR: Absolutely!

CHERYL: I did a collection. It's for an art installation. With the contributions of many people on Facebook, I think I have several dozen of them now. Only one brain injury one. My friend, Dave Parkin happened upon the conversation. Love Facebook. And he said, "How many people with a brain injury does it take to change a light bulb?...Er...um...uh, I got this one. Gimme a minute," [both laugh]. Any other disability jokes?

TAYLOR: I have blind and seizure jokes.

CHERYL: That guy. You told me about this guy. So if you could retell some of his jokes since he's not here.

TAYLOR: Oh yeah.

CHERYL: OK.

TAYLOR: The one that started it all, was--I stole it directly from Jurassic Park. What do you call a blind dinosaur? Do you think he saurus? Do you think he saur us? What do you call a blind dinosaur's dog? Do you think he saurus rex, [both laugh]?

CHERYL: I was like, Fido?

TAYLOR: Why don't blind people go sky-diving? Cuz it scares the dogs.

TAYLOR: What do you call an epileptic in a pile of leaves? Russell. I mean, some of them are really terrible!

CHERYL: I love that.

TAYLOR: What do you call a boy with epilepsy in the bathtub? A Jacuzzi. What do you call a boy with epilepsy holding a glass of milk?

CHERYL: A milkshaker!

TAYLOR: A milkshake.

CHERYL: Milkshake. He told these?

TAYLOR: He made these up, yeah!

CHERYL: This young person with epilepsy made up these jokes.

TAYLOR: Yes.

CHERYL: Ok, I just want to be clear that this is coming straight from the horse's mouth.

TAYLOR: Yes. And my favorite one: What do you call a boy with epilepsy in the garden? A seizure salad [both laugh]. He made that up!

CHERYL: Can't top that. Well, you could top it with seizure salad dressing. But you cannot top that. Now I respect that not everybody will find these jokes funny. I do respect that.

TAYLOR: Yes.

CHERYL: What's important is that when the person with a disability makes up a joke about their disability, don't get defensive. It's ok. It's ok to laugh. It's funny.

TAYLOR: Mhmm. And he loves to tell these jokes to strangers, which is the coolest experience to watch. Because he'll say, "I have a joke for you." And then, he'll tell this joke. He's so excited. And then they see him as a kid who's funny and can laugh.

CHERYL: Oh!

TAYLOR: It is amazing to watch because he's no longer this poor, pitiful angel who needs prayers. He is a funny child who can laugh at his situation.

CHERYL: And he sees himself as a funny child, right?

TAYLOR: Yeah.

CHERYL: So, thank you, other person on the street, for seeing him the way he sees himself.

TAYLOR: Uh-huh. He has changed a few perspectives. People have come up to us later and said, "That was a really funny joke you told. Thank you so much." And they take that with them into their lives.

CHERYL: Taylor, happy spring to you. Thank you so much for coming to be on my show today. I really appreciate it.

TAYLOR: Oh, thank you for having me.

CHERYL: It was a lotta fun.

[music]

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, WhoAmIToStopIt.com.

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