TIOW - S2E5 - Expectations

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Episode Description: This week, we're talking about the expectations other people have for us. Eric talks about moving out of his parents' house and the sacrifices he makes to live independently. Kai contrasts two bosses he's had – one who makes assumptions about autistic people, and one who values his ideas and contributions. Ally and Becca talk high and low expectations and the dignity of risk.

Kai 0:00
Don't let the world treat you like a man child. Let them treat you like a human

Becca 0:13
Welcome to the Telling it Our Way Podcast,

Becca 0:15
I'm Becca

Ally 0:16
and I'm Ally In this podcast, we bring you stories by disabled people about disabled people, stories from the daily lives of self advocates with intellectual and developmental disabilities.

Becca 0:26
These are real people with complicated lives. They don't want your pity and they don't exist to inspire you.

Ally 0:31
This is not inspiration porn. Becca, can you think of a time when you were really feeling the pressure of high expectations. You had all this on your shoulders, something like you felt like you really needed to succeed at something pretty difficult,

Becca 0:48
constantly answering this question right now, what if I don't answer it? Right

Ally 0:50
Okay, okay. I didn't intend for the question to have such high stakes, but

Becca 0:59
No, but I think probably something that we can both relate to you and I both have PhDs, and I think that in that process, there's a lot of expectation that you're doing something, quote unquote important and meaningful right. There's a lot of pressure to get it right.

Ally 1:15
Yeah and I definitely think I felt a lot of anxiety, especially from family who had never gone to college before to sort of keep working and pursuing that higher education and that kind of anxiety from those high expectations played out in really physical ways, right, having a lot of like indigestion, right, or panic attacks or things like that. So I think that high expectations is something that folks with particular body minds that succeed well in, let's say, higher education settings, you feel the pressure of those high expectations.

Becca 1:48
Oh, the fear sweat.

Ally 1:49
Have you had the experience? That's sort of the opposite where you have sort of low expectations. So for instance, I'm a terrible athlete. I know it's probably a shock to everybody listening. I have such an athletic build, and I remember I got called in my friends were short a player on a basketball team, and they just sort of called me in at last minute, and there were such low expectations that I would do anything actually useful for the team, and what that did for me was it made me feel really, really unimportant, and I just goofed off like it exacerbated the low expectations. I just goofed off during the whole game.

Becca 2:33
Yeah, nobody cares

Ally 2:34
Nobody cares. So I'm just gonna sort of be a jokester about this, right?

Becca 2:34
Yeah,

Ally 2:34
Have you ever had that experience with low expectations?

Becca 2:40
Well, I am a woman, so

Ally 2:45
Becca, this isn't a feminist podcast.

Becca 2:48
Well, so if it's not obvious, the thing we're talking about today is, expectations and and something that we know a lot about around developmental disability is a lot of the times people have some pretty low expectations for what people with developmental disabilities are going to do in life, right? And that can often mean a lack of opportunity, right? You're not given the same kinds of opportunities as other people, because there's an assumption that you can't do this

anyway, like you and your and your basketball story, right? You know, I was thinking about this episode topic today and earlier this year on National Down Syndrome Day, which is in March, there was this really great campaign that came out with this actress, Madison Tevlin, where she's an actress with Down syndrome, where she said, assume that I can so maybe I will. And she talks about going through all these different things, having a drink, living on my own, you know, having sex, having a relationship, these kinds of things that often people with developmental disabilities, there's an assumption that they won't, and so the opportunities and the support don't present themselves.

Ally 3:48
You know, I think that I loved that campaign, and I think one of the things that I like to teach about in the beginning of our Disability Studies courses is this idea that when you pity a disabled person, or you think a disabled person is really inspirational, they're the same. There are different sides of the same coin, and what unites those things is this idea of low expectations. It's a low expectations coin, and on one side of that coin, you have the pity, because people look at you and they assume you're never going to do anything that's worthwhile, right? And that's where that pity comes in and the other side of that coin is the inspiration. Well, you're such an inspiration, because I had such low expectations for you that anything you do is sort of an inspiration.

Becca 4:30
You got here to the grocery store and you're picking out cucumbers. Wow, it's amazing, right? Yeah, they absolutely are kind of two sides of the same pity coin.

Ally 4:41
So we're gonna have two stories today that are about expectations, and often the low expectations that people with intellectual and developmental disabilities experience on a daily basis. So first, let's hear from Kai, who's talking about two different work experiences.

Becca 4:57
Let's listen.

Kai 5:02
All right, let's take it from the top. Then my story is about, well, people who viewing me as with my both autistic abilities and my gender quality. So a couple of years ago, oh, I was working at a retail business. I won't give the information on that, for the most part, the people were actually very kind, generous, nice, helped me out through the various some basics of the job, nothing too out of the ordinary. The only member who was actually a bit of an issue. was actually one of our managers. They basically wanted me to do something that was specifically meant for them to do, only not for a either a new employee or any one of that nature. The reason she basically did it was because she assumed that all men would be capable of doing the heavy lifting or anything like that. Ironically enough, depicting men as huge, strong people and women as pretty much weak, which is again ironic, but also slightly hilarious. Essentially, I was just lifting up some rugs and putting them back in place, which doesn't really help when they just pop back

out from the other side. Some of these rugs were about as large as a table. And to be frank, the job was also, um, cutting me down on hours from what I normally would make, which pretty much was almost peanuts at that point. So I started looking for another job. I eventually did find another one, but that one was only temporary due to my other disability, which was, of course, my physical inability to, well, lift heavy objects. I mean, I may be a bit strong, but I'm not that strong. I won't go too deep on that one. So moving on to my current job, which was actually my most recent one the people that I'm working at now, which is a more factory based job, or production, if you want to go with that, had been actually much more courteous with people with Autism, and actually had pretty much a multi generations working on it. No matter the disability, though, we actually all started helping each other out in various ways from probably even the beginning to this very day. It did not matter whether our physical capabilities or mental capabilities were hindered. We actually all still do what we can to help each other out. If there's an issue that we find with our workstation, that we do now, we actually put in the idea, and the company will look into it and see if there's actually something that we can do, or if it's something that's going to be put on the back burner, and we'll go to it in about a couple of years. For basically one of my ideas, they actually take everybody into consideration, even those who have a disability. I basically came up with a few protective barriers to keep the parts from scattering all over to the floor and forcing me to actually get up from where I'm working, and having to pick them up and then just put them back in the bin for the most part, that actually had fallen through and We've now gotten protective barriers and started to produce the products much more efficiently without the hindrances. Some of these other ideas have actually been given by other employees, some of them also under the same scale and as me, for the autism spectrum, and for the most part, we've all been basically not only just a company that is working you together as like a simple job, but it all honestly starts feeling more like a family. If I were to actually give any words of encouragement for anybody else working in a job that they actually love. It's actually to be better at treating us more like humans, rather than treating us like machines. As a side note, if you suffer from the autism spectrum, don't be afraid to ask for help when it is needed. Don't let the world treat you like a man child. Let them treat you like a human

Becca 10:26
All right. Thank you, Kai for that story. What I like about that story so much is that we get those two different experiences. We get the one experience with the kind of strange expectations that don't match kind of who Kai is as a person, and then we get this other work experience where he's working now, where there's an expectation that he's not just doing his job, but he's contributing to making his workplace better for everyone, right? And his ideas are taken seriously, and that's a part of what that job experience is like. And so I think it's a really good model of what happens when we toss those low expectations out the door.

Ally 11:01
Yeah, and you know, we have, last season, we did an episode on work and workplace experiences, which some of these themes around low expectations definitely resonate with those experiences. And we're going to have another episode later on this season that's going to touch more on workplace experiences and so but I really liked to think about Kai's story as a

sort of symbolic of the broader understanding of expectations, if we were to sort of think about expectations in a big way, not simply about workplace expectations.

Becca 11:31
Yeah, I think that's a really good point. I think one of the things I want to talk about before we get into this next story about where does some of these low expectations come from? And I often think the kinds of low expectations that are the hardest to get rid of are the ones that come from kind of well meaning people who are trying to protect you, who are wanting to make sure that you don't make a mistake, or wanting to make sure that you're safe, right? And in this field, we sometimes call a pushback against this the dignity of risk, right? So giving people an opportunity to make choices, even when those choices might have some consequences associated with them,

Ally 12:07
right. So we have sort of a well meaning paternalism, but it prevents people from having autonomy, right? And autonomy is a basic human right.

Becca 12:16
Right, So if you're really buying into independence and autonomy and agency, that means sometimes letting people fail, right? And that's really what the dignity of risk is all about. Because if we don't let people try, then we also don't let them succeed.

Ally 12:31
Wasn't there, Last season, we had a contributor that came on and talked to us about, I'm trying to think of what he called it, something like the grilled cheese test, like, if you're living at home, if in the middle of the night, what is it called? Burrito

Becca 12:46
It's the burrito test, it's how you know if you're living in an institution or not, are you able to wake up at 2am and make a burrito for yourself?

Ally 12:53
Right that's the dignity of risk, right? Is it actually a great idea to eat a burrito at two o'clock in the morning? I mean, maybe for many people, it disrupts your sleep, schedule, your digestion, all these kinds of things, but it's your basic human right to be able to make that choice.

Becca 13:06
Right exactly. That's the dignity of risk in a nutshell. That's a great example, but I think I want to hear another story,

Ally 13:12
Awesome!

Ally 13:13

So with this in mind, let's hear from Eric.

Eric 13:27
When I was born, I was two pounds and four ounces. 90 days early, my umbilical cord was wrapped around my neck. This happened back in 1985 and technology was way different than it is now. When I was born at the hospital, the doctors came in and told my mom and dad that they wanted to give me away. And my parents were like, no, they didn't want to do that. They are going to figure it out along the way. I had extreme difficulties in high school because people only saw the wheelchair and they didn't see the man in the chair. They don't see that. I'm able to tell people how I feel. They just like, well, he's in a chair. He don't know shit. And I really don't like that. Dealing with public schools. I was in special ed classes. My mom and dad were my advocates through my school career, and they had a hard time dealing with the school system. The school system only felt like they should only learn, adding and subtracting and learning how to tell time and money. That's it. My parents would help me study during summer vacations, and I would learn the stuff that the school system didn't want me to know. It's been a battle. I graduated from high school in the class of 2004 on my graduation day, my mom made my custom made suit. When they called my name, the whole graduating class and my family were chanting my name as I walked the stage at the theater, I remember it like yesterday. I told my mom, you upstaged me at graduation. And she was like, No, I didn't, we both worked for that diploma, so I let her have it, because she's not lying. I credit my mom for my school career.

Eric 16:20
In 2013 I got into an argument with both my parents. The house that I grew up in only had a bathroom upstairs and one in the basement. I would go to the upstairs bathroom. I hated it. It was like 15 stairs. I had to go up and up and down and then a landing and find more stairs. Then you up at the top level and you go to the bathroom. So every time I had to go to the bathroom, I had to keep going up and down stairs, and that's only because physical therapy and occupational therapy told my parents I needed to do that because of my cerebral palsy. One day I couldn't make it to the bathroom, and then I had an accident, and then my mom and dad were like, since you had an accident, you won't go to work. I was like, Man, that when you when y'all come back, I'm not gonna be here. We believe when you'll see it. So they go to work, and then I do a little bit and grab my and leave when I go to work, I didn't come back after.

Eric 18:01
I was able to call my caseworker at the Board of DD. The board of DD is the Lucas County Board of Developmental Disabilities. They have places to put you if you are dealing with stressful situations or life threatening situations. They have housing called respite. I moved into respite which is supported living to be honest, respite is almost like jail for people with disabilities, and they tell you what time to take a shower, what time they eat dinner, what time to go to sleep, what time to go to work. I did this for seven years because I'm my own guardian.

Eric 19:03
I was able to move out of this situation and move in with my best friend. We were best friends for 13 years. I met him back in 2010 and we stayed friends until he died last February. I am

more responsible now because I had to go through so much hardship back then. It's a lot of sacrificing if you want to live on your own. I work at a store now, 40 hours a week. It's a lot of sacrifices. I miss birthdays, kicking it with cousins and hanging out with my roommates. You can't go to all the rec gyms and hang out when you want to. You can do that if you choose to stay in an adult Day Hab Center. I hated it because they treat you like a baby when you're really not a baby. But sometimes I'm like, dang, why am I working so hard? And it's because I don't want to sit on my and collect the check. I want to improve and get better. I've been at my job for four years, and I'm working on getting another job. Bills are piling up, so something gotta give. I'm working on getting a house and getting a car, because I feel like if I'm able to drive, I'll be more independent, because I will be able to leave when I want to leave and not use paratransit. I have a full time girlfriend, and it is like having a full time job. There are a lot of times that she wants me to do stuff, and I couldn't because I had to work. It's good that I have a girlfriend, though, she's able to pick up on my mannerisms, like, if I'm happy, mad or sad, and she's able to talk to me, eventually down the road, she will be my roommate, probably before we get married,

Eric 22:09
I want to inspire other individuals that have a disability to try their very best, having faith in God. Help me through a lot of stuff that I went through. It requires listening and staying still and being patient and not going off and doing your own thing. I done that before, and it never works out the way you wanted to when you should have stopped and waited. My parents always encouraged me to want to do whatever I was giving 100%

Becca 23:01
All right. Thank you so much to Eric for that story. I think there's a lot of really good stuff in there about kind of both the expectations that other people put on Eric. He talks about, you know, being in school and only ever being perceived as like the guy in a wheelchair, right, that can't know anything about anything, or not being taught the things that he wanted to be taught. But I think there's also some stuff in there about the expectations now that Eric puts on himself right as a person who's working full time, who's making some sacrifices in his life to not have as many opportunities for social events or things like that, in order to maintain the kind of life that he wants to live.

Ally 23:37
Yeah, that paid work is symbolic to Eric of meeting society's expectations for him. And I think it's sort of notable that Eric went through public school and that the options given to him were self-contained classroom experiences where disabled kids are not interacting with other able bodied kids, and they're in classrooms where the curriculum is not appropriate, right? So we have a law in this country that says in education, you have to be given the least restrictive environment, and yet, because of funding and because of how school systems shake out, that doesn't always happen. And certainly in Eric's case, he was not in the least restrictive environment for him, right? He found himself wanting to learn more, but not given the opportunity to do so.

Becca 24:28
Yeah,I mean, it sounds like we need to do an episode on education at some point.

Ally 24:31
It sounds like Season Three to me.

Becca 24:35
Right, so again, listeners, if you have a story about education that you want to share, we want to hear it.

Ally 24:44
Before we end, I want to thank our contributors, Eric and Kai, our associate producer, Conor Smenner, our intern, Ava Gottschalk and our Telling it Our Way advisory board members, JoRita Fox, Quinn Thomas and Gavin Dailey.

Becca 24:56
And special thanks to WGTE and always our producer. Chris Peiffer,.

Ally 25:01
To access transcripts for the show and any other show notes, please visit wgte.org/our way. I'm Ally Day

Becca 25:07
and I'm Becca Monteleone, and you've been listening to Telling it Our Way.

Speaker 1 25:13
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Speaker 1 25:16
voices around us. WGTE is

Unknown Speaker 25:18
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