

TIOW - S2E9 - Advocacy

Air Date:

Description:

Jordan 0:00

When someone tells you no, prove them wrong. Keep pushing, break boundaries, keep fighting. Never give up.

Becca 0:15

Welcome to the Telling it Our Way Podcast. I'm Becca

Ally 0:18

and I'm Ally

Becca 0:19

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.

Ally 0:28

These are real people with complicated lives. We don't want your pity, and we do not exist to inspire you.

Becca 0:34

This is not inspiration porn.

Speaker 1 0:43

All right, okay. So today we have a very exciting episode. We are doing an episode on the topic of making change, and it includes two returning storytellers today, and both of these storytellers are going to talk about some events in their lives that have been really pivotal to them becoming self advocates.

Ally 1:04

You know Becca, our intro talks about how we bring stories from self advocates, but I'm not sure we've talked much about what self advocates are, or the movement that led to self advocacy. Do you want to tell us more about that?

Becca 1:04

Oh, yeah great point. I mean, so we use this term self advocate all the time when we're talking about people with intellectual and developmental disabilities who are either speaking up for themselves or speaking up around important policy issues or social issues that matter to them. But where does this term come from, and where does this movement come from? So we've

talked a little bit on the show before about some of the history around people with intellectual and developmental disabilities, particularly, you know, the rise of institutionalization. So many people with intellectual disabilities up until the mid century, the 50s, 60s and 70s, spent a lot of their lives in these isolated institutions. But then in the 70s, we start to see the deinstitutionalization movement, the closure of these institutions. And there's a lot of reasons why this happened. Some folks point to there's this really famous television expose about the Willowbrook institution on Long Island by a very young Geraldo Rivera called Willowbrook The Last Great Disgrace. And when this aired on television, it created this big public uproar that in some ways, was really pivotal to this movement to close institutions. But the reality is that there were movements within these institutions for a long time among the residents, and that's true in the United States, and it's true abroad. The self advocacy movement itself began in most accounts, and actually began in Sweden in 1968 so there was this, this group of Swedish parents who were running this organization for their children with developmental disabilities, and they had this motto that they said, we speak for them. And then one day, they were having this meeting, and there were a bunch of people with intellectual and developmental disabilities, there who were like, no, no, no, wait, wait a minute. You don't speak for us. We speak for ourselves. And that was kind of the start of this self advocacy movement.

Ally 1:16

Yeah and we might say that the self advocacy movement in the United States came out of some organizing from those incarcerated by Fairview state institution in Oregon, and with the first conference of people with intellectual disabilities called People First. And Linda Gear is one young woman who really spearheaded that movement. And that first conference was in 1974 and had over 500 attendees.

Becca 3:36

Yeah, and People First is a huge, now international kind of network of grassroots self advocates. We have a People First Toledo here. In fact, JoRita Fox, one of our advisory board members who you listeners might remember, just guest hosted for us. She was one of the founding members of People First in in Toledo, and People First has done a whole lot of work in a lot of different places, in part to close institutions and in part to provide community supports for people with intellectual disabilities who are now living in their communities, doing policy work and on all of this kind of thing, including insisting on representation in places like state boards of developmental disability or as JoRita talks about, she's currently the president of The Arc of Ohio.

Ally 4:23

Yeah and what is so awesome now is that we have older generations of self advocates that can mentor younger generations, and the two stories that we have today come from this younger generation.

Becca 4:34

Yeah, that's a really great point. Both of our storytellers were born in what I would call the kind of post ADA era, right? And so are coming in with a sort of whole different landscape than what

existed prior to 1990 and so the first story we have comes from Jordan, who listeners may remember. Last year, he shared a story about working at the Toledo Zoo and becoming the dancing parking lot attendant. He also talked a little bit about how some of his experiences with bullying and in school helped him to kind of find who he was as a person. And so this is another story about his experiences when he was younger, and some early experiences of discrimination that have really shaped him into who he is as a self advocate today. And so let's hear from Jordan.

Jordan 5:21

What can I say when I was little, I was a pretty wild child. I was unpredictable. I was always escaping the booster seat. Once when my mom was doing the dishes, she turned around and well, I was gone. She looked everywhere, up, down, left, right, across the street, down the street. Then she decided to go back to the same spot where I was in the tree. She looked up, and there I was asleep, just very peacefully. To this day, she still can't figure out how I got up there and looked so peaceful. When I was in high school, we had an assignment where we did research on our names. I looked up my name and found my last name is Barriola versus Greater Toledo, YMCA. And I said, Mom, you got some explaining to do. Turns out, when I was little, I went to the YMCA for daycare. The person who worked with me left dropped her bags just to get out of dodge at the YMCA and told me I couldn't come back. They didn't know how to handle me. Every day care center turned me down like a bag of Skittles because I'm autistic. My mom went to the Ability Center for some help. She eventually got a good lawyer and a dear friend. We won the case, and the YMCA had to support me when I was in high school. I wanted to volunteer at one of my favorite places, the Toledo Zoo. I had to get approval from the school and get good grades, which I did. Then I had an interview and a test at the zoo. My mom asked to read the test questions for me to make sure I understand, but they say he's fine. He could do this on his own. The test was too much for me, and I hid under the desk, like in case there was a bomb going off. A few days later, they called and said I couldn't do the zoo program. That's when, quote, "Mama Bear", comes out. She said we could come down with the full force of the ADA or she could work with them to train them. She helped them learn about people with autism. We had to start a program with people with disabilities that could learn with a peer. I was a guinea pig subject zero. The program is called SNAP program. I've had a whole lot of pressure to prove that I can do this. I really did. Now there's a whole program for other people with disabilities to volunteer at the zoo, and even unpaid jobs. In 2017 I got a paid job at the zoo, which took five tries. Now a whole branch of obstacles and opportunities for me to tackle my old buddy at the zoo told me once, if it's at home, just leave it at home, if it's at work, wipe your feet before you walk out that door. It really helps. And now here comes the most difficult challenge. No dramatic pauses, please. Driver's License, that is the most excruciating task ever I work with Jackie, bless her heart, who taught me the do's and don'ts, ups and downs, every crevice you could think of. I took the practice test over and over and over and over and over. I took the written test at the DMV, the one by the Stranahan theater, and I passed on the first try. But that's when the 2020s pandemic and my temps expired. How dare they I had to take it again. It took three tries, and once I passed it, I went outside the door. and just do my celebrate dance. I work with James at the UTMCC, and he taught me by taking me to a drive simulator. It's like a video game, but it's a little different. It tests your reflexes and your reactions. I also had to

keep out an eye for your surroundings, pedestrians, wildlife, people park on either one side of the road. It depends on which road you are traveling. And finally, I come to the most difficult challenge, getting behind the actual wheel of a vehicle and maneuver through the traffic cones. And finally, I took the test. I kept thinking wipe. Feet, wipe your feet. And after two tries, I passed. Woo hoo. Now I can think about growth my career. There are jobs at the zoo that requires a driver's license that I can try for now, the African carousel, the train and the golf carts, and then that patience happened, and I'd start driving the safari train. Woo hoo. But now my biggest goal right now is to make places more disability accessible. I made a video with Team Salute for the zoo, and I made a big impact, and now I'll have to tackle a huge challenge, and that is to make Cedar Point disability accessible. There's a very big difference between the zoo and Cedar Point, because the zoo is just acres of land. Well, Cedar Point, it's a huge island. It's going to take me about three to five years to get everything to put into place, to send into motion. I want to make everyone's life simple, life, not difficult, life, especially people with developmental disabilities. I look back on my ups and downs, on my journeys, and now I see how far I came. I'm a trailblazer. I lead by a good example. Plant seeds, let it bloom. But truth be told, I'm not fully satisfied yet. I want to keep climbing those mountains until I reach that peak, when someone tells you no, prove them wrong. Keep pushing. Break boundaries. Keep fighting. Never give up. Don't let yourself get down if you have self doubt and think you've had enough. Wipe your feet. Get out there. Make a difference. Let your voice be heard for the future. If I had a book and my quote would be, don't listen to those naysayers. Prove them wrong. You know why? Because I'm the voice of the voiceless.

Becca 12:15

So what I love about Jordan's story is that he has had this drive to be a self advocate from a time when he was really, really young. I mean, he talks about being discriminated against in his preschool setting, and so seeing his mom kind of step up and fight for his rights, deeply informed who he became as a self advocate as soon as he was able to start to voice his own desires and needs. And what I also love about Jordan is that he is constantly identifying new challenges and goals around advocacy, both for himself and for the people around him. Actually, I just worked with him and our local board of DD. He was asked to do an accessibility audit for a local organization, and so I got to see the product of that report that he's been doing. So it's just really cool to see all of the different ways that he is impacting our community with his kind of strong self advocacy identity.

Ally 13:10

And we have another story today who comes from another really strong, empowered self advocate, Cass. Listeners may remember Cass from last season when she and her boyfriend Brad shared their story of romance. In this story, Cass shares with us a hobby that she has that's helping her become an even stronger self advocate. Pun intended.

Cassandra 13:31

Hi, my name is Cassandra, and this is my story about power lifting and becoming the very first female power lifter for Special Olympics in Lucas County.

Cassandra 13:51

I joined the power lifting team in March of 2017 before I started the team, I was going to the gym by myself. I told my SSA I was looking for a team. She found a team and who to contact. I started training at Super fitness with coach Brian Strock When I first arrived, I realized I was the only girl. It was all guys. I wasn't nervous. I was so eager to join the guys that tried to intimidate me, they said, You can't lift a lot so I said, just watch me. We have to work and train so hard, it's like you have to give all your blood and sweat to it. I work out twice a week, on Tuesdays and Thursdays from 4 to 5pm when we lift we do bench pressing and deadlifts. A bench press is when you lay down on a bench and bring the ball bell to your chest and lift it up. A dead lift is when you bend your knees, lift the ball bell up, and then lean back. But don't lean all the way back, because you don't want to hurt your back. I started training in October to June of 2018 for the Ohio Summer Games Ohio State University. When I arrived at the Summer Games, I had to weigh myself in to find out what Division I will be in. It's my goal to stay in the lowest weight division, which ranges from 120 pounds to 125 pounds. I weighed in at 124.5 pounds. It was crowded there because all the different counties family members and coaches were arriving. I put music on to pump me up. I listened to the song Royal. You gotta get yourself pumped up before you go out to compete. You are allowed to go to the weight room. You lift the ball, but not the weights, so you don't tire your body out before the competition. I hear them call my name and say my category is coming up. I was going up against one other girl from another county, Up first is the bench press competition. I go and lift at competition for powerlifting at the state games. You have to listen to the commands real close because they are picky about it. My highest lift was 85 pounds. The other girl did not make any of her lifts that means she wasn't able to bring the ball bell all the way up. We go to sit at the side and wait for the award ceremony. They say my name and say you go up to the first place stand. I was so relieved because I had worked so hard throughout the year, eating the right food and training with the guys and my coach Brian. Next, we did the deadlift competition. I lifted 190 pounds. I ended up winning that gold medal too. At the award ceremony, they say you are the all around gold medal winner for state competition, for Special Olympics. I was so excited. Families and coaches took my picture and I did the Wonder Woman pose. I am now a three time state champion for powerlifting. Fast forward. I am now the four time state champion for powerlifting. And that's not the only first thing I have accomplished this year, I became the first woman with a disability from Lucas County to join the Ohio Developmental Disabilities Council. I wanted to tell this story because females can do what guys can do, and it doesn't matter if you have a disability.

Ally 17:34

What I love about Cass's story is that she takes us into a place where we don't often see or think about people with intellectual and developmental disabilities, the space of fitness and sort of self improvement, right? And competitive sports, I think sometimes we tend to pigeon hole people with IDD as as being just sort of participants in, like, something like Special Olympics, which we've had stories about before, certainly, but not really in terms of thinking about a young, powerful woman like Cass in a weightlifting gym.

Becca 18:11

Yeah, and I think it's really important to remember that, like, self advocacy isn't just something that happens, right? It's something that takes work and practice and support, and we know that Cassandra, or Cass and Jordan both have these communities of self advocates that they work within and that they learn from, and that they teach, and that's true for all of us, right? And so, you know, I think particularly it is most often that people with intellectual and developmental disabilities are told that they are not capable, or that they are not able to contribute, or that they are not able to speak for themselves, and so someone else has to do that for them, right? And so keeping this idea of the dignity of risk kind of center feels really important for me, right, letting people speak for themselves and express what it is about their lives that they find important and that they value. And that seems to be the kind of key. The nugget of self advocacy, for me, is that it can't just be something that the person does, right? You have to also be in a community that's willing to listen.

Ally 19:11

Yeah, and I think that's a part of the goal of this show, which is to give self advocates a platform to talk about the things that they really care about.

Becca 19:19

Oh, yeah definitely, and it's really great to have these two really strong self advocates in our community who are able to share some stories today. You know, I will also share that Cass has recently been appointed to the Ohio Developmental Disabilities Council, which is an appointment by the governor for this statewide Council. And so it's been really great to have these really, really strong advocates here who can serve as a model for people who are still learning their way around self advocacy.

Ally 19:55

Before we end I want to thank our contributors, Jordan and Cass, and 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 and a special thanks to WGTE and our producer, Chris Peiffer

Becca 20:09

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Ally 20:15

I'm Ally Day

Becca 20:15

and I'm Becca Monteleone and you've been listening to Telling it Our Way

Speaker 2 20:24

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