TIOW - S3E1 - Moving Out

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***Episode Description:****Telling It Our Way* is back for Season 3 with a big episode on leaving home for the first time! Kristina shares about all the skills she needed to learn, from bill-paying to cooking her grandmother's macaroni and cheese. Jisele talks about learning to be independent when the people around her doubt she can be. Becca and Ally share the numbers on where people with developmental disabilities live and what barriers prevent them from being in their communities.

Jisele 0:00

For a long time when I was living at home, I felt stuck like my everyday was the same.

Becca 0:14

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

Ally 0:17

 and I'm Ally

Becca 0:18

 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 0:33

 Yeah, this is not inspiration porn.

Ally 0:40

Hey. Becca, Welcome to season three of the award winning Telling it Our Way Podcast.

Becca 0:44

Oh my gosh. Ally, I just like got a little thrill doing the intro just now. I'm so excited to be back. I can't believe we've already had two seasons and more than 24 storytellers come on the show

Ally 0:56

 I don't either, and I think this season is going to be even more jam packed with storytellers. We even have been so fortunate to really be able to recruit from all over the country,

Becca 1:08

That's right. And also spoiler this season, for the first time, we are expanding internationally.

Ally 1:15

What is so exciting to me is that our storytellers can have a platform for telling their stories. So let's get on with this episode.

Becca 1:22

Okay, all right, I hear you. I hear you. So we're gonna jump right in, because that is what brings our audience. Here are these awesome stories, and so today, we are going to think about moving out, right so that the two storytellers we have for today are gonna give you their take on moving out of their family homes and going into their own places for the first time.

Ally 1:43

Becca, do you remember what it was like when you first moved out?

Becca 1:48

Of course I do, but to be fair, I'm actually not sure it counts, because I moved in with my sister, so I don't know that my moving out story is as dramatic as some of the ones we'll hear today. What about you? What was the first meal that you cooked in your first place that was all year round?

Ally 2:07

I'm pretty sure it was boxed macaroni and cheese and frozen peas, because that was basically a standard in my 20s. So nothing super gourmet, but it did the trick. Who do we have up first?

Becca 2:21

So our first storyteller, Kristina , she's going to share her experience moving out of her grandmother's house and learning all the things that she needed to live on her own, including it sounds like cooking a little bit more advanced than you do

Ally 2:36

Yeah, it's a good thing we have storytellers.

Becca 2:39

All right. Let's hear from Christina.

Kristina 2:45

My name is Kristina , and this is my story. In 2009 I moved out. I was living with my grandmother. I was raised by my grandparents. My grandmother did not want me to move out. At first, I talked to her about it, but she said, You're not going to do it. She kind of blew it off. Then I made preparations to do it. I started looking for places. I went to the Social Security office to become my own payee. She had to sign off from being my payee. She did that. She said, Well, if you're going to do it, then just take care of yourself. It's a little bit hard moving out, because you have to adjust to not living with whomever raised you. Even though it's scary, you can do it. It was scary for me, but I wouldn't take it back for nothing in the world. I had to learn to pay bills. I understood how to do it, but I had to get used to doing it myself. I had to learn to write a check, to write a money order, go to the bank, deposit my own money, take out my money, go shopping and make a grocery list and stick to the grocery list, because when I lived with my grandmother, she made all the decisions and did all the shopping. I love my grandmother, macaroni and cheese and greens. Now I can make it on my own. I really enjoy being able to make my own decisions. When I lived with my grandmother, she kind of did everything for me. She didn't allow me to make my own decisions. Once I got out on my own, I started finding out who I was and who I wanted to be. Instead of listening to everybody tell me what I should do and shouldn't do and what I should be, I kind of became my own person. I really enjoyed living on. My own and being able to come and go as I please. I want people to know you can become your own person. Make your own decisions. It takes a lot of courage. You have to be strong to go out into the world that you are not used to being in. And sometimes you mess up, but you can learn and you can do better. My grandmother passed away in 2023. Before she passed away, we had a conversation. She told me she was proud of me and happy I was living on my own and being independent. She was very proud of me.

Ally 5:41

 I think it's really awesome to hear Kristina talk about being independent and how proud her grandmother was for her to have achieved this. Is this common for people with intellectual and developmental disabilities?

Becca 6:00

Oh, I'm so glad you asked. Let me bring you some stats. And so one of my favorite places to get information about people's living situations is something called the residential Information Systems project. This is a project that is based out of the University of Minnesota, but essentially, what they do is they have a database for where people with intellectual and developmental disabilities who are receiving long term supports and services live. And so I'm looking through their data, and their most recent kind of nationwide survey was in 2020, and so I think sometimes there's this misconception that people with disabilities always live in facilities or live in kind of specialist group homes or communities. And what, what this Residential Information Systems Project found is that the vast majority of people with intellectual and developmental disabilities live either in their family home or their own home in the community. So what they found nationwide, 61% of people live in the family home, and 11% of people live in their own home, which is a home they own or rent, with either themselves or roommates. You know, whatever that living situation might be.

Ally 7:16

And that's not too different, or is it from Ohio. So it looks like we have some statistics in Ohio where we record our show with 73% living with family and 16% with their own home. So it's a little bit different. So it trends differently depending on what state you're looking at.

Becca 7:35

Yeah, but what that says about Ohio is that more people are living in their communities than living in, you know, specialized services or institutions. You know, I think what they see overall, is that over time, we're seeing a lot more people living in the community and living in smaller sized housing, so having kind of less people with intellectual and developmental disabilities living together. The other thing that I think is really important to point out here is, I think this other major misconception we have about housing and disability is that it's more expensive to support people to live in the communities than to live in somewhere like an institution, right? People assume that you have more people living together, so it costs less to provide them with support. And in fact, the data says the exact opposite. It's much less expensive to support people to live in the communities than to live in these large scale institutions.

Ally 8:30

And it wasn't really that long ago, where by the mid 20th century, it was kind of assumed that if you had a child with a developmental or intellectual disability, they would eventually go live in a group home or an institutional setting that families would, of course, not want to have them living in the community or living with them, because it would be too much of a burden. And we saw some change, you know, with the disability rights movement and with some of the advocacy from the Kennedys in particular, that that changed some of that, so that we've seen this trend of people living more often in their own communities and not being isolated and living longer lives as a result of that.

Becca 9:07

Yeah, totally and. And now the push is for, you know, we have people living in the community, but like that, data says a lot of people are still living in their family homes still. And so now the push is for, how do we support people who want to live independently, to be able to do that, which I think is a great segway into our next story. And so do you want to introduce who's talking next?

Ally 9:29

Yeah, so next up, we have Jisele , whose experience of leaving home was a little more spur of the moment, not quite as planned as our first storytellers, and it might be something that our listeners can relate to you.

Jisele 9:46

 My support. Growing up, I had a lot of people do things for me, which as a kid, you know, it's nice, but when you get older and you're still having people do things for you, when you have someone always do it. for you, you don't really feel as independent as you would like to. It's kind of discouraging at times. It's very discouraging, like why would I want to move out when I could go from relative to relative or, you know, get married and have my husband take care of me. Well, I was a very curious kid, so in return, I became a curious adult. I wanted to do things with everyone else. It just might take me a little longer, because I'm legally blind, but I still wanted to do things on my own, so I had to learn a lot of things by myself. I learned how to do makeup when there was a time where I actually wanted to wear makeup. I learned how to do my own hair, like curling iron, a straightener, and most recently, I learned how to cook with an air fryer. So this air fryer has an app, and I could navigate it with VoiceOver, so it's very accessible for me. So there are features, and you know, they have the options for, like, air fry, bake or boil. If you click one of those options, they have like, a pre heat time, like a already standard time, or you could raise up the temp or time, whatever you prefer on. And also the app has this feature where, if you take a picture of the package, it would also tell you like the recommendation time and temperature. Well, for a long time when I was living at home, I felt stuck, like my everyday was the same, and I was always constantly waiting on someone to cook for me, or like I was always relying on someone else. But now that I'm living with a friend, I do things for myself a lot more like I cook for myself. When I want to eat, I just have more space and time to, you know, learn things that a lot of people probably have already learned at a younger age. I think I outgrew my situation, and I've always wanted more, and I knew I wasn't going to get it in the area I was living in, because I didn't have much opportunity for jobs. So I moved to an area where there is more opportunity, not just for work, but, you know, just things to do. All my friends live in this area. The hardest part about it is getting switched over to counties. There's a lot of delays to getting, like, programs and stuff. So yeah, I switched over to the county I live in. Now, it's a few months' process because there's a lot of waiting lists, but once you're in, they're really helpful. It's just a long time before anyone can get back to you, just because there's so many people wanting services as well, everybody knows, pretty up in the air. So that's kind of exciting in a good way, not so much in a scary way anymore, because I've been, you know, waiting for this for a very long time. So I think I'm at a point right now where I'm ready for whatever comes next, hopefully work so I could build some work experience to add to the resume, because it's pretty small right now. But yeah, I want work experience so one day I could have my own boutique. I think it's important to share my story, because I think a lot of people who are labeled with any type of disability, their label becomes a label. So they automatically hear legally blind, just assume that not only that I can't see anything in general, but also that when people hear that, they automatically talk to the person who's with me, not directly to me, like I'm not even a person anymore. And from a very young age, I was able to I advocate for myself, so I think it's important to push the label and try to do things for ourselves and be encouraged to do Things like everyone else, and not let others tell us what we can and can't do, because we're the only ones who know that.

Becca 14:45

 What I think is so interesting and great about Jisele’s story is the way that she talks about being able to resist some of those low expectations that the people around her had, right? She talks about growing up and having everyone assume they had to do everything for her, but now she's moved out into her own place and learning to do those things on her own, and how valuable and important it is to just come in with that mindset, that I can figure this out.

Ally 15:31

Yeah, I love that too, and that she's able to leverage technologies like her air fryer and her smartphone to make dinner definitely a step up for my box macaroni and cheese,

Becca 15:42

right? It seems like both of these storytellers have kind of schooled you on cooking this episode, but

Ally 15:49

absolutely,

Becca 15:49

 I wanted to share just a few more pieces of data that we have around you know, it's not just attitudes that prevent people from living independently in their community. There's some other stuff that comes up too. So for example, when we think about just like how physically accessible are our houses and apartments, and you know what the data says from the US Census Bureau, the the American Housing Survey, is that there are almost, or more than double the number of households that have people with physical disabilities in them, then there are accessible housing units, right? And so what we find is, you know, we've got that more than double the number, but really only 9% of households who have someone with a physical disability live in an accessible home, right? So people are making adaptations to their homes all the time just to kind of live in them, because we just simply don't have enough accessible housing.

Ally 16:47

Yeah, the housing stock is low. We have a housing crisis in general, and in states with a lot more older housing like on the East Coast, that housing crisis is really severe for people, particularly those who are low income, right? Which many, many disabled people are because of how we provide subsistence, you know, for them, but also because renovating older houses is really difficult and hard.

Becca 17:11

Yeah, absolutely. And then this kind of second issue that comes up is around the cost of housing. And so again, coming from the American Community Survey, what we find is that more than 7 million low low income renters with disabilities are paying more than 30% of their income per month just on rent, and 4 million are paying more than half of their income per month on rent. And so that's creating this situation where people are kind of not able to afford their housing, or if they're able to afford their housing, they're not able to afford the other things they need to survive. And then the kind of final thing that I think is making it difficult for people to live independently in their community is the lack of direct support professionals, which is a topic we're going to visit later in the season. But the idea here is that there just simply aren't enough people who are working in the industry to provide support for people on a day to day basis. But we'll get to that later. We've got a lot coming up this season, but before we end, we just want to thank our contributors, Christina and Jisele , our Associate Producer, Conor Smenner and our Telling it Our Way advisory board members, JoRita Fox, Quinn Thomas and Gavin Dailey.

Ally 18:23

Special thanks to WGTE, and our producer, Chris Peiffer, to access

Becca 18:27

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Ally 18:34

I'm Ally Day,

Becca 18:34

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

Unknown Speaker 18:41

W G, T, E, voices around us.