

## Episode 23 - From Nursing Home to Living in the Community with Michael Martin

Mike Hoenig:

Hey everybody, it's Mike Hoenig with the Iowa UCEDD. The UCEDD stands for University Center for Excellence and Developmental Disabilities. We are housed at the University of Iowa as part of the Center for Disabilities and Development. And we want to welcome you to Disability Exchange. We, in addition to partnering with the Center for Disabilities and Development, we partner with the Midwest[ern] Public Health Training Center at the University of Iowa, College of Public Health to produce these podcasts. And we're very grateful for the work that they do to support us. We have a great guest today who will be introducing shortly, but first of all, I'd like to turn this over to my esteem colleague, Judy, to introduce herself.

Judy Warth:

Welcome back, Mike. I hope you had a good vacation.

Mike Hoenig:

I did. Thanks.

Judy Warth:

And I'm Judy Warth. I'm here at Iowa's UCEDD you said as well, and excited today for our interview. So Mike, I'll let you get us started.

Mike Hoenig:

Okay. Well, our guest today is Michael Martin, and Michael wears many hats within the disability advocacy community. Michael, first of all, welcome. Thanks for joining us today.

Michael Martin:

You're so welcome. Thank you for the opportunity.

Mike Hoenig:

So we'd like to start out by just asking you to tell us about whatever you'd like to share and are comfortable with in terms of how you are connected to the disability community. How do you have personal experience with a disability? Well, let's start there. Do you have a personal experience living with disability?

Michael Martin:

Yes, I do. I have a pretty detailed personal experience. When I was a young adult, I developed a lot of medical problems related to my cerebral palsy. And that is why I'm an advocate right now, because believe it or not, I've lived in a nursing home. And I saw the mistreatment of people and I saw that the services were not being met and I decided to make lemons out of lemonade.

Mike Hoenig:

Wow.

Judy Warth:

You know, Michael, since our listeners can't see you, you were in a nursing home. So, how old are you?

Michael Martin:

I am 29 and I was in that nursing home at the age of 25, I believe.

Mike Hoenig:

And you were probably the youngest person there by a lot.

Michael Martin:

Oh no, there was one person younger than me, but yeah, I was one of the youngest. Like there was a guy that was in the nursing home. He got shot and was paralyzed from the neck down. So he was in the nursing home. He was 18, but yeah, I was one of the youngest people there.

Judy Warth:

What was that like having everyone surrounding you being significantly old or different stage of their life?

Michael Martin:

The hardest part for me at the nursing home was watching people die. We wouldn't see them actually die, but we would constantly see when the coroners would be there and stuff.

Mike Hoenig:

Mm.

Judy Warth:

Yeah. Your whole social network are people who are aging in the final stages of their life and you're a young man.

Michael Martin:

Yep.

Mike Hoenig:

You did say you lived in a nursing home. So that, tells me that you no longer do. Can you tell us about some of the steps that you and maybe others took?

Judy Warth:

How did you escape?

Mike Hoenig:

Yeah. How'd you get out?

Judy Warth:

How did I escape?

Mike Hoenig:

Let's get right to that point.

Michael Martin:

How did I escape? Well, I had to have surgery. I had to have a bladder poot and a colostomy and my mom just came down, threw a bunch of stuff in a box and took me back to live with her. Because we didn't want me to get an infection after surgery.

Mike Hoenig:

Oh, so you live with your mom?

Michael Martin:

No.

Mike Hoenig:

Oh.

Michael Martin:

I just, that's how I first got of the first nursing home that I was in.

Mike Hoenig:

I got you.

Michael Martin:

And then I had the surgery, I had multiple complications from that. I went to another nursing home after that to recover. And then honestly I can be kind of mouthy so, they got tired of putting up with me. So, this social worker from Mosaic, which I lived there for a year and a half. And then eventually my medical problems got better and they stabilized. So that's, how I got connected with MFP. Because when you're in a facility, you only have like \$50 to your name. So, I needed a support system other than my mom and other than a man group. And what MFP did for me is they got everything set up to where like they made the referral in the middle of May. And I was moved by the end of September

Judy Warth:

For our listeners. MFP is Money Follows the Person, which is a partnership for community integration project that moves people out of intermediate care facilities or nursing homes into community living situations.

Michael Martin:

And anyways, there's this huge misconception out there. Like if somebody lives in an ICF/ID, people just assume that their consumers needs are going to be met. And that's often not the case. Like not only do

they have limited resources, their family members don't have control over any of their medical situations and the facility kind of just takes over.

Mike Hoenig:

You're in a house now, right? Where there are a lot fewer, how many people do you live with now?

Michael Martin:

I live in a REM home and there are two other individuals that live here.

Mike Hoenig:

Is it part of what's called the Home- and Community-Based Services or HCBS program?

Michael Martin:

Yes, sir. That is correct.

Mike Hoenig:

And I'm guessing not only you, but your family, you have a lot more flexibility now in terms of your healthcare and some of those decisions?

Michael Martin:

Oh yes we do. For example, I had a nurse in, ICF/ID, but we only saw her maybe once a week. Now living in the community, I have a nurse that comes out every 60 days to make sure that I get the bath aid services that I need and go over any medical stuff. But actually, when a loved one moves out of an institution and into the community, they might not get everything they want right away, but their quality of life will improve dramatically. Like I was still in the ICF when COVID hit. Well, I couldn't see my family at all because we were on lockdown.

Mike Hoenig:

That must have been really tough.

Michael Martin:

Yes. And I ended up having another medical situation pop up because we were on lockdown. So needless to say, when my vascular pump went bad, my mom was surprised because she was like, what? She didn't have any idea because, like I said, she couldn't see me. So.

Mike Hoenig:

Right.

Judy Warth:

You know, Michael, if I were going to ask you, what are the three most awesome things about making the changes you've had in your life so far? Moving from nursing home to nursing home, to hospital to now, more of your own home. What would be the three best things about it?

Michael Martin:

The three best things about it are you get to interact with people your own age. Like, it depends on where you're at, but I have two really awesome roommates right now. And I obviously would not have my jobs if I wasn't living out in the community. And the other thing too, is people know me through me. They don't know me through a facility.

Mike Hoenig:

Mm, exactly.

Judy Warth:

And you know, Michael, now you're speaking my language. Tell me about these jobs.

Michael Martin:

Well, I've got the job with MFP. I've got the Olmstead Consumer Task Force, we're trying to get me a job out in the community. I believe we're looking at a retail store, or we're looking at maybe an observation technician. They go and they work in the hospital.

Judy Warth:

What would be your dream job? We may have a listener, who's going to go, "I got his job!" What would be your dream job?

Michael Martin:

My dream job would be to just land a full time gig doing advocacy work, or maybe even being on their radio or something, doing a disability show or something.

Judy Warth:

Uh-oh, Mike. He's after our jobs.

Mike Hoenig:

Uh-oh, oh yeah. And perfect medium -

Judy Warth:

He wants this podcast.

Mike Hoenig:

There you go.

Judy Warth:

Just watch out for him. Danger, danger.

Mike Hoenig:

I know, but Hey, it's a great opportunity. And doing podcasts and things like this, there are more and more people that actually, this is part of what they do. So that's, pretty fun. You mentioned something called the Olmstead Task Force. Tell us a little bit more about that.

Michael Martin:

Of course, the Olmstead Task Force, it's been around for quite a while. It's been around since 1999, I believe. I found out about it through Mosaic, because they were looking for people to work. But the story behind it is really neat. I don't think Money Follows the Person would even exist if it wasn't for the Olmstead Task Force. Because the Olmstead Task Force was brought about, because two consumers, they lived in an institution, but they had trouble getting out into the community because they couldn't

get services. So they got fed up and got a lawyer, and that's how the Olmstead Task Force was kind of formed as I might say.

And the Olmstead Task Force is put in place to make sure that people have the resources and have what they need to live a meaningful life in the best way possible for them and their loved ones. And we oversee everything from accessible housing to access to the community. And then we have Olmstead meeting that is basically the plan that we're going to do. And then we also make sure that providers have what they need so they can continue to serve the disabled population.

Mike Hoenig:

That's a broad range. And what I think is really neat is that you actually receive services through MFP and to get out of the ICF, the intermediate care facility. And now you're giving back by serving on the Olmstead Task Force. So you really must be passionate about not just for yourself, but for people all over Iowa.

Michael Martin:

Well, the thing is Mike, I don't want other people to go through the things that I went through because nobody should have to go through what I went through. No 20 something year old person should have to live in a nursing home.

Mike Hoenig:

Absolutely.

Judy Warth:

Amen. So what do you do with your days now? Now that you've moved through that, you're doing some advocacy work. But tell us what else are your days like now that things are loosening up a little bit with COVID. What do you, how do you fill your day?

Michael Martin:

We've been going to the movies. We went and saw the movie, The Underdog, that's a true story with Kurt Warner. And then I was able to go to the Make Your Mark Conference with the Ambassadors. And I've just been doing a lot of work functions.

Mike Hoenig:

You know, I don't think we've really talked much about the Ambassadors and that's another cool program that I know that you're quite involved with. And I think with the Make Your Mark Conference, which our friends at the DD Council host every year. You presented, it was quite a moving presentation at Make Your Mark. So tell us a little bit about what the Ambassadors are and what they do.

Michael Martin:

Well, the Ambassadors are like me. They have lived in an institution basically, and we've all received services through MFP, I believe. But the Ambassadors are like made up of, I believe, 10 individuals that have transitioned successfully out into the community. And we also have two parent guardians, so everybody can get a guardian's perspective.

Mike Hoenig:

And what do you do?

Michael Martin:

Basically the purpose of being a community ambassador is basically to educate and support people that want to move out into the community. And basically we do presentations. And then in the beginning, when I first started this job, they actually did a video of my story. And the purpose of that video was to get people's attention and really let them know that, Hey, this is possible.

Judy Warth:

What advice would you give to somebody who was living in a facility and wanted to be like you?

Michael Martin:

I would say, be patient, nothing is perfect at first. And I would tell them that there are going to be bumps in the road in the beginning, but I would say over time things get easier. And I would also point out like, they could get a job. They can work for both rehab, they can go to dayhab, they can do whatever. In an ICF, you can't do that.

Mike Hoenig:

Absolutely, that's true. One of the things that I thought you were also going to maybe mention that struck my attention early on is that you said, you can be mouthy and at the nursing home, they got tired

of hearing your concerns. And so they connected you up with Mosaic, but it sounds, I mean, that was sort of your road to freedom, so to speak. I mean that got you to where you are now.

Michael Martin:

Yes, my mouth did. Yes.

Mike Hoenig:

And so we have mouths and it's important to use them to express ourselves. And I think that many of us that have experienced disabilities sometimes don't recognize that and say, well, I guess we probably really can't say anything. And it sounds like you did, and look where you've come now.

Michael Martin:

Yeah.

Judy Warth:

Michael, are there things that you are dreaming of haven't happened in your future, goals that you've set for yourself that you want to see? You've now moved out of a nursing home, you've moved into your own place. You're doing advocacy. What are your plans for the next five years?

Michael Martin:

Well, I guess it's always been one of my dreams to go to the Golden Gate Bridge and I guess just spend more time with family and I've thought about applying to be on National Task Force, that's in Washington DC. I thought of doing that.

Mike Hoenig:

Wow. Is there anything particular about the Golden Gate Bridge that interests you or is it just kind of one of those places that you've always read about and seen?

Michael Martin:

It's one of the places that I've always wanted to go and visit. And I had looked at the Golden Gate Bridge as a kid, especially when I was having surgery or whatever, and be like, "okay, this is what you are going to get to go do eventually", so.

Mike Hoenig:

I love that you're sticking with your goal. That's important, it certainly sounds like it's achievable now that you're out in the community.

Michael Martin:

Yes it is.

Judy Warth:

And I like that your goals really encompass some travel, some growth professionally and family. I think it's important for our listeners to understand those are important to all of us.

Michael Martin:

Yep, they are. And I have two nephews, their names are Finn and Liam, and then I have a niece that's on the way.

Mike Hoenig:

Cool. There wouldn't be any Irish-

Judy Warth:

Congratulations.

Mike Hoenig:

Yeah. So there wouldn't be any Irish involved in your family, would there?

Michael Martin:

Yes, there is there. There's Irish and German. That's where we get our, we don't put up with crap attitude in, that's where we get our sassiness from.

Mike Hoenig:

Oh!

Judy Warth:

Sassy!

Michael Martin:

When the Irish and German get together, you better watch out.

Mike Hoenig:

Get your Irish up, as they say.

Michael Martin:

Yep.

Judy Warth:

Well, Michael, we have a question we ask everyone who we've done this podcast with about 50 years from now, when they look back and they go, Michael Martin, what do you hope that your legacy will be? What do you hope that people will say about you when they look at your whole breadth of your life?

Michael Martin:

I hope that I leave the legacy behind that yes, you can have struggles and yes, you will have challenges, but it's how you deal with them. And it's how you rise to the occasion, and it's you overcome obstacle. And you can choose lay down and fret or you can fight. And my hope would be to get the message across that everybody deserves to be happy. And even when you are down and depressed, if you just fight and get through it, your life will be better.

Judy Warth:

That is wisest wisdom for everyone.

Mike Hoenig:

It is. And because you're telling about both sides of the coin, it's not just all fun and games, but it's definitely worth it. The end result, I mean, you're only 29. So you've got all kinds of great things to look forward to, but you've come so far. And before we wrap up, Michael, is there anything else that you would like to share?

Michael Martin:

No.

Mike Hoenig:

We managed to cover it?

Michael Martin:

Yep.

Mike Hoenig:

Anything from you, Judy?

Judy Warth:

No, but you know, Michael, on behalf of all of us at Disability Exchange where we're working on centering and uplifting the voices and the lives of people with disabilities, by sharing your stories, we want to thank you. This partnership that we have here with our community and our advocates. People like you, who are creating change. Members of the University Center for Excellence and Developmental Disabilities here, at the center for Disabilities and Development and our esteem partners at the University of Iowa Midwestern Public Health Training Center allow us to bring this podcast to you. On behalf of all us, Michael, thank you so much for sharing your story.

Michael Martin:

No, thank you.

Mike Hoenig:

I would just like to second that, and also thank our great audience out there, listening. We just really want to encourage you to share the podcast with others and to tune in once again, very shortly when

we will have another great guest for Disability Exchange. So thank you, Michael, and thank you all out there in podcast land.

Caitlin Owens:

Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for Disabilities and Development at the University of Iowa. Special thanks to Kyle Delveau for the music contribution.