

Episode 3: Finding a Voice with Ed Esbeck

Mike Hoenig:

Oh hey, everybody, it's Mike Hoenig with the Iowa UCED, University Center for Excellence in Developmental Disabilities, and we're excited to welcome you to another disability exchange podcast. How is it going there, Judy?

Judy Warth:

Good. Co-pilot today is none other Judy Warth. We're excited to bring you yet another story of disability and leadership and life that is far more than the disability itself.

Mike Hoenig:

Absolutely, Judy. You're so right about that, and I think our guest is the perfect person to talk about that, because he has accomplished so much that's gone way beyond his disability. And then instead of talking about him now, I'd like to introduce him and welcome him. His name is Ed Esbeck and he lives in Iowa City. He's a coworker and a friend, so welcome, Ed.

Ed Esbeck:

Thank you.

Judy Warth:

Ed, you want to tell folks a little bit about yourself?

Ed Esbeck:

Well, I grew up in Uganda. I was raised there, and I moved to the United States in 2014. And I worked in my life to be a leader and extend to that, I learned my leadership in Uganda, but I didn't know what leadership was back then, but I was always doing stuff for leadership.

Judy Warth:

So you've always been a leader is what you're telling us?

Ed Esbeck:

Yeah, but I learnt more of things not only myself but advocacy, being a leader for other people. That's what I learnt. Being a leader, you only think about yourself first, but then you start realizing that things

are not all about you. Things are about other people and how their voices are important to you. That's what I learned over this time.

Mike Hoenig:

Ed, I am really fascinated to hear about your leadership experiences in Uganda. How old are you now?

Ed Esbeck:

I am 22, becoming 23 in October.

Mike Hoenig:

22. So that means when you were in Uganda, let's see, you moved here when you were about 15 years old, is that right?

Ed Esbeck:

Yeah.

Mike Hoenig:

So, that means you were younger than 15 when you started being a leader in Uganda. Can you give us a couple of examples of now that you look back when you started your leadership work there?

Ed Esbeck:

Yeah. First, it was all about me and my leadership skill. For example, I was a school leader, a school prefect at the age of 13, at a school in Uganda. One of the things I did there was to make sure that people don't jump line for food, because people were fighting to get into line for food, so I was the one who made the line to step up for food. And then the other example I can give is that at the age of 14, I walked out of the classroom because I wasn't provided enough education, and when other people were finishing their schoolwork, I was completely confused and I didn't know how to make myself be heard in that way, so I walked out of a classroom. And that is another advocacy that I learned how to become.

That gave me the confidence because I was worried that my dad was going to kick me out of the school, instead my dad supported me in that move. My dad was a big advocate for me into that area of advocacy for myself. Step into a school that was supposed to provide people with disability including in Uganda, but they were not doing it well. So started that movement of advocating for change for myself, but at the end of the day, I felt this is not about me. This is about everybody else to see that example of me. And that is why that goal of advocating for others, because I was... I think my dad always says, "You

were born as a leader." That's what my dad always told me. The moment he saw me, he was like, "You were born as a leader."

I was like, "I don't know that. I never thought about that." I came a long way to being a leader, and I'm continuing to learn and continuing to grow into leadership.

Judy Warth:

What is your job now? What's your job title? What do you do?

Ed Esbeck:

A self-advocacy coordinator, and I do a variety of leadership. I work for the UCEDD just like you guys, and I educate people with disability on self-advocacy for their selves, and become their own leaders. I sit on different boards to help the UCEDD bring more self-advocacy into the table. Also, on the LEND team, and LEND has given me the opportunity to learn leadership is not only for other people. I'm doing a lot of advocacy for others more now. It's not all about me. It's about all of us.

Mike Hoenig:

That's great. And it sounds like a really exciting job. We've heard you use the word advocacy a lot, and I think a lot of our listeners will know what that means, but I'm guessing that some people probably won't, so why don't you give us your definition of advocacy and self-advocacy?

Ed Esbeck:

Advocacy is the way to reach out to other people, and self-advocacy is when you advocate for yourself. You speak up for yourself and when things... either you're frustrated with something and want to say something out to people, you can tell them that, "This is what I want to do. This is what is important for me to do." But you putting your voice there is important and that is what a self-advocate do and educating others, empowering other people to become their own advocates, that's the way how I can explain advocacy, Mike.

Mike Hoenig:

That's helpful. So you're speaking for yourself, and you're also helping others to learn to speak for themselves and maybe in some cases joining in with them to speak about things, right?

Ed Esbeck:

Yeah, and also learn that they have a voice to change the world as I do.

Mike Hoenig:

Very important.

Judy Warth:

Ed, as you're helping others to gain their voice so they too can change the world, what sort of guidance, what sort of things do you do to help people do that?

Ed Esbeck:

One way is I teach them how to advocate for their self, then I give them ideas. I kind of make presentation because I want them to be part of the community. And if you're part of the community, one thing you're going to see is how you can bring those voices together and empower them so that they become leaders in their own way. They can find their own voice by educating them to become leaders in their own way is the most important thing. And that's how a leader is supposed to lead, by encouraging others to follow them. And by me teaching them about advocacy has engaged me to learn and to grow as well as them.

I think about that every day, that how can I make a difference to someone else? How can I make a change for someone else so that they can have their own voice into the community and they can have a voice to share with others.

Judy Warth:

Will you talk a little bit about some of the differences? I mean because I think having a voice is so important to you because in Uganda, many people have no voice, whether they have a disability or not. And you've come here and now you've got a big voice.

Ed Esbeck:

Yeah. And again, a lot of people with disability are left behind, because we grow up... when we don't have a voice. I lived that life of being not able to advocate for myself. But I did it in many ways of becoming a leader in that way. And that's what I learned, that many people are calling to us, grow without a voice, but they learn their voice as they use it the right way. By thinking about that, just like to the Uganda, there are some people with disability among us, we're being hidden away from the community. We don't have a voice to speak for us even in Uganda because most of us have been taken out of the community, as people with disability. That's becoming a chance of being able... for me to experience that, versus in America, where I hold these rights and I can perform my right. As someone with disability, I don't get to vote in Uganda. But here I'm able to. That are some of the things I've seen in Uganda growing up.

Mike Hoenig:

Wow.

Ed Esbeck:

But here, I'm able to. Those are some of the things that I've seen overall in Uganda growing up.

Mike Hoenig:

Those are many, many differences. Sometimes in this country, we think that... and I do believe that we have a long way to go for disability rights in this country, but then you think about being in a place like Uganda, and people with disabilities are even more shut out. Tell us a little bit about how you got from Uganda to the United States.

Ed Esbeck:

I was adopted in 2007.

Mike Hoenig:

You were adopted in 2007?

Ed Esbeck:

Yeah. And that was the time my dad was talking to us about coming back, but I only spent two years with my dad. A year with my dad at that time. I couldn't fly... I just spent a year with my dad at the time, and I had to go through all the difficult stuff. And becoming a citizen in America was hard, and it is even more harder now than it was because I just hear people spend money to come here ever year. And I experienced a lot coming here. But my moving here, my dad was saying that, "You should stay in Uganda for another four years," because we visited in 2008. Just to see family so that I learn the family that I call family right now. Because I didn't know them then. And so I had to navigate that whole system to learn my family because that was difficult for me.

To learn the family without seeing them. Calling them name without seeing them. We visited in 2008. Because my youngest and oldest brothers came before me to the US, so they've been having more area than me in understanding of that, of family ideas and family characters. I grew up in a group home not knowing what a family is like, and for them it's confident that I can be with a family after all. My dad was remarkably happy to get me out of Uganda and to bring me to United States. The most important thing

is we picked Iowa as we were looking for places to stay. Minnesota was one of them, but we picked Iowa because most of the family member are in Iowa.

That gave us the idea that we should move Iowa part of the family. And so I kind of got into the flight on the 14th. They moved in through the summer of 2014. I moved in the end of summer because I had to take care of medical issues in Uganda. So I ended up flying by myself in United States.

Mike Hoenig:

I did not know that.

Judy Warth:

You know, Ed, I don't know that it's clear in what you've said that in Uganda, you lived in an orphanage, didn't you?

Ed Esbeck:

Yeah.

Judy Warth:

And your dad adopted you and brought you here?

Ed Esbeck:

Yeah.

Judy Warth:

It's not like all these guys from Uganda got on a plane and said, "Where will we go? Shall we go to Iowa or Minnesota, or?" But yeah, your dad is from the Tipton area, right?

Ed Esbeck:

That's where most of my family are, but we picked Iowa City because of school. That's what we came for, because we didn't have a good education. The education we had was expensive, so my dad, he could afford it but it was too much for all of us to be in international school. The best schools were international schools in Uganda. And that was hard for him to pay for. And again, he decided that we should move to United States because of education, providing that we are American citizens who never

lived in the country before. And that was like we were growing up thinking that we loved America. We wanted to come here.

But again, the experiences we had in Uganda were really great for us as people of color, as our culture related to us.

Mike Hoenig:

So you went to high school in Iowa City then, right?

Ed Esbeck:

Yeah. I went to City High. When we first moved here, I started my junior year in high school, so I didn't have the whole four years of school, and I just wanted to do everything I can do, take all the opportunity I can enjoy, and get into work. And that's what I did.

Mike Hoenig:

That's good. I'm sure there were a lot differences in your school experience between Uganda and the United States.

Ed Esbeck:

Yes, there were. One, teachers in America cares more. And they cared really for me. Whereas in Uganda, in many schools I went to, apart from the international school which I attended, most of the schools I went to were local from my baby to when I went to the international school. Again, I also went to... had some home schooling, so that the opportunities learned from being able to stay at home and learn from home gave me that big opportunity to learn. I was home schooling for a while. That was 2009 and 2010. We went to home schooling. 2011, we were moving around Uganda. My dad was working back then, and he was teaching us how to teach in local language.

That's where we went into home school. And that gave me the opportunity to learn the skills that I wanted to learn. Home school was probably the best school I ever attended until I came to the United States. And international school, worked kind of well in terms of providing the information I needed. But they didn't give me enough information that I really wanted until I came to United States and learned everything all over again. I again took a normal American teenager's school. So I didn't have those experience back as a teenager. I learnt my teenager-hood here.

Judy Warth:

What sort of things did you enjoy about high school here in Iowa?

Ed Esbeck:

Oh. Being a homecoming king and...

Judy Warth:

You were the homecoming king?

Ed Esbeck:

I was.

Judy Warth:

Congratulations.

Mike Hoenig:

Did you have a crown?

Ed Esbeck:

I did, and I still do have it in my room.

Mike Hoenig:

You do?

Ed Esbeck:

Yeah. I never gave it away.

Judy Warth:

What else was really awesome about high school here at City High?

Ed Esbeck:

I just think what really goes more into the participation with the team, the leadership of the team and the teammates that I had around me, from cross country, basketball to track and field.

Mike Hoenig:

Oh, the team.

Ed Esbeck:

Those gave me those opportunities to learn and to be part of the team of City High, because I didn't think I would fit into a school. When you come into a school at the age of 15, you're like, "What can I do?" And with all the culture change of that. What can you do? I remember showing my first year of high school because I was still new, I was still using to stuff, and I remember talking to my dad about... my dad asked me, "How did school went?" I told him it was terrible on the first day. This is my school year, because of culture. So I had to learn the American culture in a difficult time, because I have not lived here long, and I'm in this school where I can... I didn't know where my classes were so I was late for each and every class because I wasn't successful.

And it became a priority for me to think about it this way: if I'm done with high school, then I'm able to go to work. And it has been ever since the time being at work have been the hardest thing for me because of being on time. And being on time was one of the hardest thing. I'm learning to do that a better way, and that's one thing that I continue to grow into because I didn't have that experience back home, because back home, they tell you that you have to be to work at this time but you come an hour late. That was the way we lived our lives. That was built in for me, so coming here, I had to learn a different way. It was difficult because I was used to stuff over in Uganda. And that was their time. According to the time. That was the issue for me to learn.

Judy Warth:

So in Uganda Ed, time isn't measured as tightly as it is here?

Ed Esbeck:

Yeah.

Judy Warth:

That would be a hard thing to... it has been a hard thing for you to conquer.

Mike Hoenig:

But I've noticed that you are on time almost all the time now, so you've obviously... I mean number one, you're 22 years old. When I was 22, I was always late for places. I don't know if you can imagine that, Judy, but I was. I was always late. In fact, I had a professor one time that said, "Is there something you can do to maybe get yourself here a little bit sooner?" And I said, "Yeah, I think I can do that." So it takes a lot of responsibility, and it sounds like... also, when it's not been such a part of the culture, that's one of many things I'm sure you've had to adapt to coming to the United States.

Ed Esbeck:

Yeah, and because you have a certain time you have to be here, and if you don't be here, sometimes people are going to yell at you. And that's something I learned over the time, that I don't want to be yelled at. I just didn't learn that way, so that I can improve on that. Technology has been helpful, and that has been the thing for me to learn, but I'm still becoming better in that area because of firstly my year as being here as well as learn a new way to be on time give me that confidence.

Mike Hoenig:

It's good. So it sounds like you had quite an experience in high school, some good stuff, some hard stuff until you got connected with some groups like the sports teams. Tell us, how did you get connected to the UCEDD? Because that's quite a thing for a 22 year old to be working in a professional role for the UCEDD. How did you make that connection?

Ed Esbeck:

So I got connected the UCEDD through Judy. And it's because I went to to the CPAC meeting. I remember that.

Mike Hoenig:

I think some people aren't going to know what CPAC is. And it's Community Partnership Advisory Committee, and it's a group that advises the UCEDD on the different kinds of work that we do.

Ed Esbeck:

So I went to CPAC. Judy invited me to speak at the CPAC.

Judy Warth:

You know what, Ed, let me jump in. I did not invite you to speak at the CPAC. We had gone on a job shadow. We'd gone somewhere.

Ed Esbeck:

Oh, yeah.

Judy Warth:

And I didn't have time to get you back to where you were supposed to go. So I said, can you go with me to this?

Mike Hoenig:

She had something she had to do at the CPAC, so we were counting on Judy, as we so often do.

Judy Warth:

So Ed goes with me. Fast forward, we start activities. Who jumps in? Now it's yours to tell, Ed.

Ed Esbeck:

I stood up and I speak about employment, about my work at HyVee because I was already working back at HyVee. And I'm already hearing information which were really good and motivating. And I was like these are the best things ever to happen to me. At this stage I asked you, Judy, but I was like this is the best thing that has ever happened to me. You asked me, "Are you ready to go?" And I said "Hey! I can't leave. I'm really enjoying it." So you took off, and when you came back, you were like, "Can we go for lunch," I was like, "Oh, yeah, we can go for lunch." That's how I got connected with the CPAC.

Judy Warth:

Yeah, I'm trying to escape the meeting, and say, "You ready to go? Do you need to go?" "Oh, no, I'm staying. I love this."

Mike Hoenig:

Yeah, I remember that.

Judy Warth:

I love this stuff. But you know, Ed, I think the way you got your foot in the door at the UCEDD was the women's march in Des Moines, do you remember that?

Ed Esbeck:

Yeah, and so going to Des Moines with Julie Christensen, who was the director at that time. I was thinking I was going to Chicago for the women's march. And I was so excited I was going but then, I heard about the Des Moines one. And then I was so excited to go to that. But I was really wasn't supposed to DC. And my dad was like, "let's think about getting a bus to this DC." But there were some people, they were going to Des Moines. And we went and asked Julie Christensen that we want to go to DC, but she was going to Des Moines at that time for the women's march that year. And that was the most powerful thing ever for me to do, because I was wearing my Ugandan T-shirt and holding a poster saying that, "We're immigrants here in the US. We should be treated as people."

That's what got Julie Christensen and talk about it and she was like, "Oh my God, I want to come and work for the UCEDD." I was like, "Oh my God, I never had that opportunity before in my life." So I started to attend... that following summer, I kind of started going to them, then the following summer of 2018, I started doing a lot with LEND. LEND is Leadership Education in Neurodevelopmental Disabilities.

Judy Warth:

What's the purpose of LEND?

Ed Esbeck:

To bring the voices to people with disability among professional, like social work, doctors and... for the first time, the person that's a self-advocate and the family advocate which have experiences in the other... it was about "it's nothing about us without us." That was the key in that of being a self-advocate.

Judy Warth:

You know, Ed, you helped craft this trainee role of self-advocacy in LEND. Do you mind sharing with people a little bit about your disability?

Ed Esbeck:

Yeah. I have a physical disability called cerebral palsy. It effects my speech, my movement and my writing, because I don't write so fast. It effects my body according to what I know. I know that everything I do, I do them slow and it effects my movement overall.

Mike Hoenig:

So when you started LEND, like you said, you're the first self-advocacy trainee. So you actually went through a year... well, two semesters. So it's like a year at the University of Iowa, right?

Ed Esbeck:

Yeah.

Mike Hoenig:

And you had all these experiences working with social works, students that are in social work and students that are going to be doctors and other therapists, so forth. And you said it was hard for you to read and write. How did that work for you to go through LEND? Because I think there were quite a few assignments that you had to do, right?

Ed Esbeck:

Yeah, there were. With assignments given to me, and being able to attend the seminars and I had to find a way for me to learn those stuff. But I also provided for this... good for me, to reach out when I needed help because I started gaining confidence and before that I was being quite, I'm going to learn as I go. But I was given all this technology and like read and write, because that was one thing I used, I first used in high school. This worked for some time very well, but then I would read everything that I needed to read and then pick out the one which I had and then I would go to Judy or Mike for clarification. Like what does that mean?

And that's the idea that yes, I can ask questions. I can reach out to people and ask questions. And that gave me that power to speak out for my need. And it brought me a big advocacy in my role. Some of those technology, I still use them today in my work. I still go for information if I need to. And I learnt how to ask for so many help because of my learning of not asking questions. Sometimes I feel like I'm relying on people so much, and sometimes I feel like I get frustrated by them not helping me so I'm going to do it on my own.

And that's what I learnt over the time, that sometimes you rely on people when they have time. But if they don't, then you're going to have to learn another way to do it. And so far, it has benefited my career, that I have to learn different ways of doing stuff, and those different ways are, try something alone and if you can't get it, ask for help. That's what I learnt to do, and I'm doing it very well so far, because I'm engaged a lot with all the coding, the codes, I have enough support now with my work. And as I mentioned, before I came to know I needed this much support that I relied on, but as I learned through them with the assignments, I learnt that I can do that by myself, and I can teach other people to do stuff by themselves.

Mike Hoenig:

And you are doing that very, very well. Ed, we're getting fairly close to the time where we need to wrap up, so we want to ask you a little bit about what legacy, what is the thing that you... what's the important thing to you as you move on in your career that you want to help to communicate to other people and that you want to be known for?

Ed Esbeck:

We're not alone in this. We are together. And the voices of advocacy we have is important. And anyone who says that they can't do it, they must prove themselves wrong by finding out what they really want to do, if they want. But they don't think about what they can do, but to think about what they can't do, and that effort comes from their hearts, be with them together and become leaders themselves, because when you lead and you learn how to lead for others, you put a voice there for others that they can do it too. And that is the most powerful message that as leaders now, our voice is more powerful than people who served us.

People who served us are just there to support us, but it's us to make a change in this world, and we can make a change if we put our mind and our effort into that change. We can do this and we prove this over and over. Every day, we see someone educate another person, that's their leadership to come and learn and grow. But being here, I learnt one thing: it is not all about me. It's all about people that I'm helping, I'm serving, I'm supporting in this moment. That's what I want my legacy to be. It's to support others become their own voice, and these are in this area.

Mike Hoenig:

And you're doing that every year through transition clinic and through now going from being a LEND trainee to supporting other trainees and other advocates. And I'm looking forward over the next years, to see where this journey takes you, because you have already learned a tough lesson about leadership being not just about you but being about the people you support. And I'm learning a lot from you as somebody that's been in this field for a long time.

Judy Warth:

You know, Ed, you gave some really good advice to self advocates. What advice do you give to people who don't have a disability, who are listening today and want to know more about... what can we do?

Ed Esbeck:

Continue to learn from people like us. You maybe the helpers in field, but we are the helpers of ourselves. We know what we need. And empower us to be who we want to be. Encourage us when this is hard for us. Push us so hard when we're not doing the right thing. Motivate us when we're doing the important work. Work like as I am doing right now. Push us hard when we are down, and that is all that I

think it's going to make us leaders in this effort to bring our voice, because your voice is as important as our voice. That is all I have to say.

Mike Hoenig:

Teamwork. Well, Ed, thank you so much for joining us. We could sit and talk another hour, and maybe we'll do that some time. We'll bring you back. But we really appreciate all of you listening to Disability Exchange, and especially, Ed, we want to thank you for taking the time out of your busy schedule, and it is a very busy schedule, to join us today.

Ed Esbeck:

Thank you for having me.

Speaker 4:

Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Development of 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.