

## Episode 15: Down Syndrome is Cool with Sydney and Kelly Von Lehmden & Tyler Green Tribute

Judy Warth:

Well, welcome to Disability Exchange. It's a podcast sponsored by Iowa's University Center for Excellence in Developmental Disabilities. Today, we are so excited because we're able to uplift the voice of people with disabilities by sharing not only the story of a young woman, who's rock 'em, sock 'em amazing, but also to hear from her mother as well, to hear about the joys and, sometimes, the hard parts of living in this world with disability. My co-host today is-

Mike Hoenig:

Mike Hoenig. And I work with Judy at the University Center for Excellence in Developmental Disabilities, UCEDD. I am so excited to be here once again. Looking forward to hearing from our guests. You're going to hear from two, as Judy said, amazing people today, and we're just going to get right into it. Our guests are Sydney and Kelly Von Lehmden. And we'll let them introduce themselves, and go ahead and tell us where you're from.

Sydney Von Lehmden:

I'm Sydney Von Lehmden, and I'm from Marion, Iowa.

Mike Hoenig:

All right.

Judy Warth:

Welcome, Sydney.

Mike Hoenig:

Welcome.

Judy Warth:

Who do you have with you?

Sydney Von Lehmden:

My mom.

Kelly Von Lehmden:

Yes, I'm her mom. I'm Kelly Von Lehmden. And I also live in Marion.

Judy Warth:

Excellent. We just saw Kelly in our office not too long ago. Kelly. It would be unfair to not mention that Kelly is the training coordinator for the Iowa Leadership Education in Neurodevelopmental and Related Disabilities, or the LEND program. And we've had several guests who've been involved in the LEND program on our show so far. And so, we've gotten to know Kelly and Sydney quite well over the past years.

Mike Hoenig:

And one of the things that's so cool about that is that so much of what LEND is involved with is, those of you who've had a chance to listen to a podcast or to know, is working with people with different types of disabilities. And so, one of the really cool things is that Kelly, besides being the training coordinator with LEND, is a mom of somebody with a disability. And so, would like to have both of you talk about your experience with disability or down syndrome. And, Sydney, if you're comfortable with this, how about you lead us off and tell us?

Sydney Von Lehmden:

I have down syndrome and it's three chromosomes.

Judy Warth:

Got a bonus, huh?

Mike Hoenig:

Got an extra one, huh?

Sydney Von Lehmden:

Mm-hmm (affirmative).

Mike Hoenig:

And you've lived, obviously, with that all of your life. Right?

Sydney Von Lehmden:

Mm-hmm (affirmative).

Judy Warth:

Does that make you extra special with the extra chromosome?

Sydney Von Lehmden:

Yes.

Judy Warth:

I thought so. I thought so. Do you have any brothers and sisters?

Sydney Von Lehmden:

I have two sisters.

Judy Warth:

Are they older or younger?

Sydney Von Lehmden:

Ellie is younger and Morgan is older.

Judy Warth:

Oh, you're the middle child?

Mike Hoenig:

Right in the middle.

Judy Warth:

Ho ho, fun.

Mike Hoenig:

Is Morgan a teacher?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Where does she teach?

Sydney Von Lehmden:

At Novak.

Mike Hoenig:

Is that in Cedar Rapids?

Sydney Von Lehmden:

It's Marion.

Mike Hoenig:

Oh, it's in Marion? Okay.

Kelly Von Lehmden:

What grade does she teach?

Sydney Von Lehmden:

She teaches fourth grade.

Mike Hoenig:

Awesome. And what does Ellie do right now?

Sydney Von Lehmden:

She's at UNI.

Mike Hoenig:

Oh, so you guys are all pretty close together. UNI is a little ways away, but not too far.

Kelly Von Lehmden:

And Ellie wants to be a teacher, too.

Mike Hoenig:

Does she?

Kelly Von Lehmden:

Yes.

Mike Hoenig:

Teachers in the family.

Kelly Von Lehmden:

Yeah.

Judy Warth:

Sydney, you have a job. Tell us about that. Where do you work?

Sydney Von Lehmden:

Mount Mercy. And I do sports laundry and I clean.

Judy Warth:

Sports laundry? I bet that stuff gets stinky, huh?

Sydney Von Lehmden:

Mm-hmm (affirmative).

Mike Hoenig:

Is that for all the sports teams that are there?

Sydney Von Lehmden:

Yeah.

Judy Warth:

What's your favorite part of it?

Kelly Von Lehmden:

The favorite part of your job? Do you have a favorite part?

Sydney Von Lehmden:

Not really.

Judy Warth:

What's the best part about having this job at Mount Mercy?

Kelly Von Lehmden:

What are some of the things that you really love about having a job? What do you look forward to doing when you get there and how does it make you feel?

Sydney Von Lehmden:

It makes me happy.

Mike Hoenig:

Good. Do you get to be around a lot of people during the day?

Sydney Von Lehmden:

Yeah.

Judy Warth:

Are they cool people?

Sydney Von Lehmden:

Yeah.

Judy Warth:

Were you an athlete when you were in high school?

Sydney Von Lehmden:

Yeah.

Judy Warth:

What sports did you play?

Sydney Von Lehmden:

Volleyball and basketball.

Judy Warth:

Oh, so now, you're hanging out with your homies at college? That is so cool. I bet that's probably one of your favorite parts is hanging out with other athletes. I remember seeing a video of you, Syd, shooting a three-pointer.

Mike Hoenig:

And you made it.

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Was that a varsity game?

Sydney Von Lehmden:

Yeah.

Judy Warth:

How cool.

Mike Hoenig:

That was very cool. And I think I remember they announced your name over the speaker, too, right?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Is that pretty exciting?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

You should tell him about what Scott Saville and what did he honor you with? Do you remember? We got to be on TV as what?

Sydney Von Lehmden:

Athlete of the Week.

Kelly Von Lehmden:

Mm-hmm (affirmative).

Mike Hoenig:

Oh, wow.

Judy Warth:

How cool.

Mike Hoenig:

How many people get to say that?

Kelly Von Lehmden:

Not many. Remember him coming to the school and-

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

Oh, my goodness. That was fun.

Mike Hoenig:

Did that make you nervous or did you think it was pretty fun or both?

Sydney Von Lehmden:

It was fun.

Mike Hoenig:

Was it? Get a little extra attention?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

That is for sure. It was pretty cool seeing you on TV, right?

Sydney Von Lehmden:

Yeah.

Judy Warth:

Where did you go to school at, Syd?

Sydney Von Lehmden:

Linn-Mar High School.

Judy Warth:

All right. Did your sisters go to the same school or a different school?

Sydney Von Lehmden:

Yeah.

Judy Warth:

Did you go to special classes?

Sydney Von Lehmden:

No.

Mike Hoenig:

Did you have a helper, an associate, sometimes?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Okay.

Judy Warth:

What was your favorite class? The funnest class?

Sydney Von Lehmden:

Choir.

Judy Warth:

Choir?

Mike Hoenig:

Choir.

Judy Warth:

Were there any classes you didn't like or that were really hard for you?

Sydney Von Lehmden:

Math.

Mike Hoenig:

I'm with you on that. Once it got past addition and subtraction, I was in deep trouble. Did your mom and dad have to help you with math problems at home?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

For homework?

Judy Warth:

Were they any good at it?

Sydney Von Lehmden:

No.

Judy Warth:

Kelly, what did you do with the school to help sit out when she was in school? Were there things you did to educate school personnel?

Kelly Von Lehmden:

Yeah. And it changed over the years. When Syd was in elementary school, I always did presentations to the class about down syndrome and what that meant. And I think it helped just kids understand that,

sometimes, Syd needed extra time doing homework or assignments. And so, we did that until she was in fifth grade. And then, we didn't do that anymore once she went to middle school and high school. But I had lots of conversations with the teachers and trying to have them look at Sydney for her strengths and that really trying to individualize her education. Because, so many times, I think we think of disability and this is where they're going to learn and this is what they're going to learn, and not necessarily individualizing it to her strengths and her interests. So she was in general education classes and she was also in special education classes for reading and math. And, Syd, I'm going to ask you, did you like school?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

Did you feel like you had a lot of support to succeed? Yeah, I think so too. And I think, for me, the most successful times advocating as a parent were when we all just rolled up our sleeves in a meeting and tried to brainstorm about different ideas and ways to do things. And then, as Sydney got older, then Syd started going to her own IEP meetings. And that's probably where we saw the biggest change in all of the teams, really listening to what Sydney wanted, what was hard for her, what she felt she needed to help with. So it changed a lot over the years. That's how we addressed school.

Mike Hoenig:

Well, in the whole disability community, we often say, "Nothing about us without us." So we have to get you one of those shirts, Sydney. I have one. It's pretty old, but I'm sure it would be way, way too big for you.

Judy Warth:

All right, Syd. So you're used to stinky laundry. Mike's going to give you-

Mike Hoenig:

I got some. Yeah, about 25 years old.

Kelly Von Lehmden:

The other thing I was thinking about that we did that might help others to know is when... So Sydney mentioned that she has a younger sister, Ellie, and they were only a year apart in school. And we also

did a peers type of group with Syd where she got to go with friends to see the counselor, or, sometimes, once a month, we would do fun activities over the lunch hour at school. And so, we did that for Syd, but we also set something up like that that was similar for Ellie, her sister, and Ellie's friends. So they also learned about down syndrome and just about disabilities in general. So if someone had a question, Ellie wasn't the only one that could answer because they were on the playground together since they were so close in age. And I think that was really helpful too, that Syd really had a lot of friends and advocates for her, but so did her sister.

Mike Hoenig:

What was it like being in school at the same time and place with your sister, Ellie?

Sydney Von Lehmden:

Playing at recess.

Kelly Von Lehmden:

Oh, you liked that?

Mike Hoenig:

You liked that? Did you like having her there at school?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

Tell them about volleyball in high school. Were you guys together in high school in volleyball?

Sydney Von Lehmden:

Yeah.

Judy Warth:

Same team?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

Yeah. So Ellie played varsity volleyball. And so, when Syd was on JV and varsity, they were practicing together. So, sometimes, siblings would get annoyed with each other. Is that true, Syd? Yeah. Sometimes, Ellie tried to boss you around, right?

Judy Warth:

Well, that's just having a sister.

Kelly Von Lehmden:

I know. And, sometimes, Sydney would boss Ellie around. So, yeah. It was good.

Judy Warth:

Sydney, what were some of your favorite things about school? What did you like about high school?

Sydney Von Lehmden:

I liked being in the band.

Judy Warth:

What did you play?

Sydney Von Lehmden:

Percussion.

Judy Warth:

And what else did you like about high school?

Sydney Von Lehmden:

Being in the choir.

Mike Hoenig:

So you're pretty musical.

Judy Warth:

And do I remember that you were homecoming queen?

Sydney Von Lehmden:

Yeah.

Judy Warth:

That is so cool.

Mike Hoenig:

That's quite an honor.

Judy Warth:

Awesome.

Mike Hoenig:

So did you have a homecoming dance and everything like that?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

Tell them who you got to crown the next year, too.

Sydney Von Lehmden:

Ellie.

Mike Hoenig:

Oh, really? It stayed in the family.

Kelly Von Lehmden:

It did.

Judy Warth:

And I need to know was Morgan our homecoming queen, too?

Sydney Von Lehmden:

No.

Kelly Von Lehmden:

She was on homecoming court, but she wasn't the queen. So, yes.

Judy Warth:

Wow.

Mike Hoenig:

Now that is a high, high standard. And was mom homecoming queen?

Kelly Von Lehmden:

No, and I was not on the court. So they didn't get it from me. For sure.

Judy Warth:

Syd, were there some things that were hard about being in high school? Some parts of school that were hard for you?

Sydney Von Lehmden:

I don't really know.

Judy Warth:

Were people always nice and fair to you or sometimes were they not?

Sydney Von Lehmden:

They were nice.

Judy Warth:

Good.

Mike Hoenig:

That is good. So maybe some of the things that would've been... You said math was hard.

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Did it help to have an associate? Were you in a special class for math?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Okay. There's nothing wrong with that. Judy, were you a math whiz, Judy?

Judy Warth:

I have splintered skills in that area. Arithmetic is very difficult for me. Calculus is not.

Mike Hoenig:

I'm just the opposite. I used to be able to do problems in my head to the point when I was in high school and, I don't know, somewhere along the way, we had to do a fairly complicated four-digit plus four-digit or something. And so, the teacher said, "Well, just work it out. Just carry the number." I said, "I have no idea what you're talking about." So then, I had to learn how to actually do these problems that way. But when it came to calculus and algebra, especially geometry, I was out. So, Sydney, I totally get it.

Judy Warth:

Syd, have you had any other jobs?

Sydney Von Lehmden:

I worked at the Marion Y[MCA].

Judy Warth:

What did you do there?

Sydney Von Lehmden:

I clocked them in and give them their keys.

Judy Warth:

Sweet. You're the hostess. Did you like that?

Sydney Von Lehmden:

I liked it.

Judy Warth:

When you were in school, did you do other work experiences where you got to try different jobs?

Sydney Von Lehmden:

Yeah, I worked at Fareway.

Judy Warth:

I remember that. Did you like that?

Sydney Von Lehmden:

Yeah.

Judy Warth:

You're pretty easy, huh?

Mike Hoenig:

You ever had a job you didn't like?

Sydney Von Lehmden:

No.

Mike Hoenig:

That's awesome. Well, CDD might be having a job opening one of these days. You could go work with your mom.

Kelly Von Lehmden:

That'd be fun. Would you want to work with me? Yes?

Judy Warth:

Would you want to work at our office with me?

Kelly Von Lehmden:

Is that a yes?

Judy Warth:

For those of you who can't see, there's a big smile on her face going, "Well, maybe or maybe not!"

Mike Hoenig:

So we - I have a question for you, Syd, that might be a little hard. I don't know, might not be the most fun thing to talk about, but we all had to go through this. And it seems like you like to be out and doing things, and so was it hard when we had to go through COVID?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

What were some of the things that made that really hard for you?

Sydney Von Lehmden:

It was really hard not having to be with your friends.

Mike Hoenig:

Yeah, I bet that was really tough. And, Kelly, if you want to jump in too, did you guys come up with any ways to deal with that? I mean, there's no way you can replace friends, but were there any things that you just tried to make that isolation, not just for Sid, but for all of you, to make that a little easier?

Kelly Von Lehmden:

We did more Zoom calls. So she did some with friends, and then I can't remember-

Sydney Von Lehmden:

And being tested.

Kelly Von Lehmden:

Oh, yeah. She didn't like being tested for COVID.

Mike Hoenig:

Oh, yeah. That's not very fun, is it?

Kelly Von Lehmden:

And then, I remember that the Transition Center, first she went to Linn-Mar and then she went to the Transition Center for two years after she graduated. And it got cut short that year because of COVID, and they did some training online. And, Syd, you really liked that, didn't you? Where you got to see your friends and talk? And so, I think that was helpful.

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

But, yeah. We'd play games at home, but, literally, we were shut off from everyone that you used to hang out with, other than through Zoom. So it was hard.

Mike Hoenig:

Yeah. I'm sure you're glad that you're able to be back at work now.

Sydney Von Lehmden:

Yeah.

Judy Warth:

Sydney, you mentioned your friends. Tell us a bit about your friends. Do you have best friends? Do you have a boyfriend? Tell me about your social life, what you do for fun.

Sydney Von Lehmden:

Well, I hang out with friends.

Judy Warth:

What do you guys do when you hang out?

Sydney Von Lehmden:

We watch movies and go out for dinner.

Judy Warth:

Cool. What's your favorite movie?

Mike Hoenig:

Tough question. Yeah.

Kelly Von Lehmden:

You like a lot of movies, don't you? And they might want to know what you and I like to watch together.

Sydney Von Lehmden:

Christmas movies.

Mike Hoenig:

Christmas movies. All right.

Kelly Von Lehmden:

We're Hallmark movie fans, aren't we? Yeah. And sports fans. Right? We like to watch sports on TV.

Judy Warth:

What sports do you guys watch?

Sydney Von Lehmden:

Iowa basketball.

Kelly Von Lehmden:

What other teams do you like to watch?

Sydney Von Lehmden:

Iowa State.

Kelly Von Lehmden:

Iowa state. And what about our favorite pro football team?

Sydney Von Lehmden:

Cowboys.

Mike Hoenig:

Cowboys. So what happens when Iowa and Iowa State play against each other? Then who do you root for?

Sydney Von Lehmden:

I don't know.

Kelly Von Lehmden:

And why do you say that? Who's the Iowa and Iowa State fan in our house?

Sydney Von Lehmden:

My mom is a Iowa fan and my dad's an Iowa State fan.

Mike Hoenig:

Oh, that's a tough one. You could root for one for the first half and the other one for the second half.

Kelly Von Lehmden:

She's a very good supporter of both in that situation.

Mike Hoenig:

Oh, that's good. Yeah. Luckily, it only happens a couple times a year.

Kelly Von Lehmden:

Mm-hmm (affirmative). That's right.

Mike Hoenig:

So you probably have all different colors of... You got the black and gold. I don't even know what color Iowa State is. That's terrible to admit. But what color is Iowa State?

Sydney Von Lehmden:

It's red and gold.

Mike Hoenig:

Red and gold? Okay.

Judy Warth:

Boy, Mike, you're out of it.

Mike Hoenig:

I am out of it. Well, it's the vision thing. I know what color Penn State is, though. They're blue and white.

Judy Warth:

And you can see blue and white, but not red and yellow?

Mike Hoenig:

That's it.

Judy Warth:

Just checking. We heard a rumor that you like to travel. If you could go anywhere, where would you want to go?

Sydney Von Lehmden:

In Colorado?

Mike Hoenig:

Colorado.

Judy Warth:

Does that have something to do with CIC, with Kaleb's program?

Sydney Von Lehmden:

Yes.

Judy Warth:

Yeah? You went and visited and you helped for a week last summer, right?

Sydney Von Lehmden:

Yeah.

Judy Warth:

And Kaleb's got a program where he's got people working in summer camps. What did you do in the summer camp?

Kelly Von Lehmden:

We just watched. We didn't really work last summer, but just met and toured the camp.

Mike Hoenig:

And who are the campers? Do they have disabilities? Or some do and some don't? Who comes there? They do? Yeah.

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

What are you hoping to do this summer?

Sydney Von Lehmden:

Working in Colorado.

Kelly Von Lehmden:

Can I come?

Mike Hoenig:

Is mom coming?

Kelly Von Lehmden:

No.

Mike Hoenig:

No? No mom?

Kelly Von Lehmden:

What are you going to do? Tell them what you want to do at camp.

Sydney Von Lehmden:

Cooking.

Kelly Von Lehmden:

Mm-hmm (affirmative). And where would you live?

Sydney Von Lehmden:

In the cabins.

Kelly Von Lehmden:

Yes. And how long do you want to go for?

Sydney Von Lehmden:

The whole summer.

Kelly Von Lehmden:

Yes!

Judy Warth:

Your mom is going to have trouble with that. And for our listeners, one of Sydney's high school friends is a man named Kaleb Cook and he just started a not-for-profit called Cook Inclusive Company. And they're

really geared at creating inclusive living and work situations for individuals with disabilities right now, by focusing on working with summer camps where they're infusing the kitchens with a small group of people with disabilities who are transitioning into work and transitioning into living more independently for the summer. And I can't think of a better place to go than Colorado for that, Syd. It's really cool.

Mike Hoenig:

I think I know of one other person that's going that's from Iowa. That actually is in our LEND program right now. So do you know if there'll be other people from Iowa going out there?

Kelly Von Lehmden:

I know that there will be other UI REACH students.

Mike Hoenig:

Okay.

Kelly Von Lehmden:

And so, yes. And then, I think there'll be probably people with disabilities from Colorado as well. And I don't know how they're identifying or sending out information about this opportunity, because we're pretty excited about it and they feel like they have support set up. Certainly, understand that, for parents, it's really hard to let go and trust that all the supports are in place that are needed, but I think we're pretty confident that this is a good fit, and we're excited for Sydney to do this and learn independence and what she wants... other opportunities. The nice thing about her Mount Mercy job is that she works during the school year. So she does have her summers off. So this is a really great fit for Syd. And I can't wait to hear about all the people that she's going to meet, too.

Mike Hoenig:

The other thing that's really cool about that is that if you ever decided that you wanted to get a different job, which you might not for a long time, but it's really, really good work experience. Really, that makes people know that you really like to work and help other people. So I think that's really awesome that you're doing that.

Judy Warth:

And most importantly, Syd, you're learning how to cook so that when we come over for dinner...

Mike Hoenig:

Yeah.

Judy Warth:

Kelly, you'd mentioned briefly about how hard it is for parents. As some of our listeners are probably parents, what advice do you give them so that they can all have an amazing young woman like Sydney, who's able to go to Colorado, and be homecoming queen, and work as an athletic laundry queen?

Kelly Von Lehmden:

Well, and she did mention, she also helps with the volleyball team. So she has a rockstar job and opportunity at Mount Mercy.

Judy Warth:

That's really cool.

Kelly Von Lehmden:

Well, I think, for advice for other parents, is always, as you're making and building relationships, remember that people really do want to help. So be constantly asking and just talking about different things that your friends and coworkers are doing, you never know when that connection might happen. I think, also, now, just knowing it's helping me because I know Kaleb and family that is out in Colorado, but, also, we learned a little bit more about rehab or vocational rehabilitation that they're able to find a job coach out in Colorado for Sydney, that her services do cover that. So I do ask a lot of questions. I don't always know what questions to ask, but I'm always trying to find out information, and I think that's really important too. So asking lots of questions, I think it's going to take a little faith that things will be okay and, certainly, trust in those that Sydney will be with. And I have a lot of trust and faith in Syd. And so, I think a good support team is what it's going to take and I believe we're building that team. So, anyway.

Mike Hoenig:

Well, and it helps that you have somebody that you already know, too. I mean, I think that's really, really amazing that he's... So, Syd, how old are you?

Sydney Von Lehmden:

I'm 22.

Mike Hoenig:

22? So is Kaleb about that same age?

Kelly Von Lehmden:

Yes.

Mike Hoenig:

So that's really awesome that as a young person like that, that he's really taking on this. This is quite a responsibility.

Kelly Von Lehmden:

Yeah. Well, he's an amazing friend, but he is an amazing person and has such large visions for the opportunities that he wants to create for people with disabilities. He actually graduated from the University of Iowa in therapeutic recreation. Is that right? I think. And so, he was very involved in UI REACH. And even in our high school, he did different fundraisers and was very involved in Best Buddies, and really just believes in their gifts and what they can contribute and believe that they're really great employees. And so, we feel really fortunate that Kaleb has been in our life for as long as he has. And he continues to amaze us with his passion, and determination, and willingness. I mean, this is scary to start a nonprofit. And he seems to have created a very supportive network as well. So he has a lot of people that believe in this mission or this vision, I guess.

Mike Hoenig:

That's great. So, as we look to start wrapping things up, we've got plenty of time, but, Sydney, I'd like to ask you a question. So just remember that people that are going to be listening to this, some people might be familiar with down syndrome and some people might not. So what would you like other people, that might be listening to this, whether they have a disability or not, or their parents, what would you like people to know about down syndrome?

Sydney Von Lehmden:

It has three extra chromosomes, and it's really cool.

Mike Hoenig:

And it's cool. What's cool about down syndrome?

Sydney Von Lehmden::

It makes me special.

Mike Hoenig:

Mm-hmm (affirmative).

Judy Warth:

I was gonna say, what's cool about down syndrome is you, Syd.

Mike Hoenig:

Yeah. Got that bonus chromosome in there. Well, Sydney, that is a really, really powerful message. I don't know if you know this, but a lot of people, if they hear the word down syndrome, they get sad or they think, "Oh, gosh. That's too bad." And you're telling us it's cool. And I just think that just brings a really big smile to my face because I think people need to understand. And, hopefully, by listening to what you've had to share today and your mom, you have a really, really full, fun life. I'm sure it's not always easy 100% of the time, but you're really living a great life. And now, you've got something really special and important to look forward to this summer. And so, I think that the whole message of down syndrome is cool, is something that our listeners and others need to really grab onto.

Judy Warth:

That's the T-shirt you should have.

Mike Hoenig:

You should!

Kelly Von Lehmden::

Oh, we should! Down syndrome is cool! Should we get those? Yeah!

Judy Warth:

You know, Sydney, one of the things that we ask people is all of our lives get marked by something that makes us special, something that we do that makes the world better or different. And we call it our legacy. How do you think you're going to change the world? What about you?

Sydney Von Lehmden::

That's too hard.

Kelly Von Lehmden::

That is hard-

Judy Warth:

It is hard.

Kelly Von Lehmden::

So would it be okay to maybe ask her what she thinks is special about her? What makes Sydney special?

Sydney Von Lehmden:

My disability.

Judy Warth:

And what is your superpower?

Sydney Von Lehmden:

I have three chromosomes.

Judy Warth:

Now, if I could get an extra chromosome, would it make me as cool as you? How come? How come? What about that third chromosome would make me cool?

Kelly Von Lehmden:

What are some of the things that we always tell you that we love about you?

Sydney Von Lehmden:

Kind.

Judy Warth:

You're kind?

Mike Hoenig:

Well, I believe that.

Sydney Von Lehmden:

And I'm a hard worker.

Mike Hoenig:

Yeah.

Judy Warth:

Mm-hmm (affirmative).

Mike Hoenig:

I don't want to put anything into your mouth, but I wonder if your parents ever tell you that you're really a good friend to people.

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

That's just what I whispered in her ear.

Mike Hoenig:

No kidding.

Kelly Von Lehmden:

Because she is such a good friend. Oh, my gosh.

Mike Hoenig:

That's so amazing.

Judy Warth:

Mike's superpower is hearing what moms whisper in ears-

Mike Hoenig:

No, I did not hear that. Just for the record. There is no way I could have heard that over my headset. That is funny. Well, Kelly, do you want to answer-

Judy Warth:

I was wondering what Kelly's legacy was.

Mike Hoenig:

Me, too. That's what I was... Oh, this is getting scary here.

Judy Warth:

Mind meld, mind meld.

Mike Hoenig:

I know.

Kelly Von Lehmden:

So I think my legacy would be that I want all of us, medical professionals, educators, community members, employers, to recognize that people with disabilities have tremendous gifts. They're really good employees, they're good friends, and that we need to look past their disability, and just to see who they are. There's so much more than a diagnosis, I think. And, also, when I think about something that I learned from Tyler Greene is he taught us that success isn't always winning the race. It's giving people the opportunity to participate or to run in a race, and challenge all of us to be thinking about how can we help everybody reach their success or their dreams, and making that happen for people with disabilities.

Judy Warth:

And, Syd, I have a question for you. This is a hard one, but you got this. What is the most awesome thing about that woman sitting next to you? Your mom? What makes her so special?

Kelly Von Lehmden:

You don't know what makes - That's okay!

Judy Warth:

Is she pretty awesome?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

She is.

Judy Warth:

Hey, Kelly.

Kelly Von Lehmden:

Yes, Judy?

Judy Warth:

I know that Syd thinks working is important and cool, but as a parent, what impact do you see that it has on her?

Kelly Von Lehmden:

I am really wanting people to understand the impact that Sydney having a job has had on her. I can't imagine her life if she wasn't able to go to work. She works four days a week, from 9:00 to 3:30. And then, during volleyball season, she's there until 5:30 or 6:00. And it gives her purpose. She has friends there. They tell her she's doing a good job. They want her to work more when she can. And I think she feels valued. It's her support system. It's her social group. And she gets to make money. And what do you like doing with your money, Syd? What do you like to buy with money?

Sydney Von Lehmden:

Ice cream.

Kelly Von Lehmden:

Ice cream.

Mike Hoenig:

Ice cream.

Kelly Von Lehmden:

So she gets to buy ice cream. But I think one of the things that has been challenging recently, and I think COVID has really made it even more difficult, is that transportation to her job is a challenge. And we've had lots of issues where her ride doesn't show up or they're late. And Syd takes her job as seriously as the rest of us. And they count on her. And so, trying to make sure that we have the right supports in place so people with disabilities can work and work in a job that they love and they feel valued is so, so important. So we're just so thankful that Sydney has this opportunity. And what's wonderful about this is they're thankful for her, too.

Mike Hoenig:

I just know, I remember my own experience when I wanted my first job. I was still in high school, I think. And I thought it would really be cool to have a job. And for those that may not know, listening out in

Podcast Land, I've been blind since birth. And I think my parents were a little, "Oh, we don't know how this is going to work."

And I kind of remember something a little similar, Kelly. I mean, I know you were always totally confident in Syd, but you were like, "Well, we're going to see how this goes." And it sounds like it's going awesomely well. And, obviously, Syd, you're the reason that it's going well, because you're putting the effort in and you're putting in your personality, because people like you. And, obviously, you're a hard worker. And so, I just think it's cool to see how all of us, we grow. And now, you're going off on this new adventure to Colorado. So you really are a hard worker. And it sounds like you like to do anything you can to try new experiences, new things. That's great.

Judy Warth:

Syd, is there anything else you want to say to us?

Sydney Von Lehmden:

No.

Judy Warth:

Has this been fun for you? I know you were nervous, but you have been a rockstar. Has this been okay?

Sydney Von Lehmden:

Yeah.

Mike Hoenig:

Are you going to go out and tell all your friends to be on the podcast now?

Kelly Von Lehmden:

Have to share the link with them, won't we? So they can-

Judy Warth:

Yeah.

Mike Hoenig:

And then, they can decide. Well, we're always looking for new guests.

Kelly Von Lehmden:

Oh, yeah. Have to keep that in mind.

Judy Warth:

That would be fun, Syd. And if you had two or three friends, we could have a party. It'd be a slumber party.

Kelly Von Lehmden:

Well, we should have Kaleb.

Mike Hoenig:

Oh, wouldn't that be cool.

Kelly Von Lehmden:

And Grace, your friend, and Syd. That would be a fun one.

Mike Hoenig:

We could do a podcast when you guys are out in Colorado and we could bring in a whole bunch of people. Campers and counselors.

Kelly Von Lehmden:

That would be fun. Wouldn't it?

Sydney Von Lehmden:

Yeah.

Kelly Von Lehmden:

Yeah.

Judy Warth:

Sydney, can you just let Mike know right now that if you're going to do this in Colorado, you're going to need me to be with you.

Mike Hoenig:

Road trip.

Judy Warth:

Yep.

Mike Hoenig:

Did Syd meet Binh last summer?

Kelly Von Lehmden:

She did. And we're hoping, Mike, I don't know if I mentioned this to you. So Binh is, I can't remember her exact title, but is going to be, I think, an assistant to Kaleb. And so, I think, if it all works out and they go to the same camp, she'll be living at the same camp that Sydney might go to, and then they could room together in the cabin. So isn't that cool?

Mike Hoenig:

Whoa. Well, Binh's pretty cool. We need to get her on the podcast one of these days.

Kelly Von Lehmden:

Yeah, we do. She's awesome.

Mike Hoenig:

Well, I'd just like to take a minute to thank everybody. All two of you, Kelly and Syd, for being such great guests. We always love doing these podcasts, but this has been an especially fun one. And I just like to thank all of you out there, listening to us, and I hope you learned as much as we did. It's just been really fun, Sydney, to get to know you better, and, Kelly, to hear your great thoughts along the way. And I'm going to turn it over to Judy to see if she has any last-minute thoughts. She's so quiet. I doubt she does. But, Judy, do you have any last-minute thoughts?

Judy Warth:

Of course, I do. I'm never going to forget down syndrome is cool.

Mike Hoenig:

Awesome.

Judy Warth:

Thank you guys so much.

Kelly Von Lehmden:

Thank you.

Sydney Von Lehmden:

Thank you.

Mike Hoenig:

So we would like to take a couple of extra minutes at the end of this podcast to pay tribute to an amazing self-advocate, an amazing young man, and a very good friend of mine. During our conversation, Kelly mentioned the name of Tyler Greene and some of the things that Tyler taught us. Tyler was 31 years old. And, at the time of this recording, it was three days ago. At the time of this recording, he was hit by a car in Waterloo, in his power wheelchair while crossing a street. He was airlifted to Iowa City and sadly did not survive. He passed away yesterday.

He opened so many eyes through all kinds of things, starting with his school career. He did an amazing video called I'm Tyler, which just talked about being a regular high school kid. And it went viral at a time when social media wasn't nearly as popular as it is now. And he launched basically his self-advocacy career from there. He graduated from UNI, and then he began working at the Waterloo Family YMCA with a program called Together We Play, which is all about inclusive recreation. He was involved with a

health provider training video, which we hosted several years ago and played a lead role in educating people about accommodating people with speech disabilities.

And so, he would've been a wonderful guest for this program because he embodies what we are doing here in terms of elevating the voices of people with disabilities. And we just felt that it was fitting to pay a moment of tribute to Tyler for all that he accomplished and for all the education that he has offered to so many people over these years.

Judy Warth:

Our deepest sympathies to his families and friends.

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.