

Lindsay edited

>> EBERT: Hello, everyone. Welcome to "Disability, Inc," INCLUDEnyc's podcast series. My name is Beth Ebert. I'm a youth and transition educator here at INCLUDEnyc. I am also lucky to be the younger sister of an awesome young man on the autism spectrum. Our topic for today will shed light on the unique experiences of people who have siblings with disabilities. This is a topic, obviously, that is very close to my heart, as I'm sure is the case with our wonderful guest today.

Without further ado, it's my pleasure to introduce you all to Lindsay Hyland. Lindsay is a sibling to a person with a disability, as well as a mother, a wife, a teacher, a member of the Sibling Committee at AHRC, the New York state representative for the Sibling Leadership Network. And the New York chapter that Lindsay facilitates is called Sibs New York (SibsNY). So much going on with siblings, Lindsay. Welcome, Lindsay. Thanks so much for joining us today. We're so excited to have you here.

>> HYLAND: Thank you so much for having me. It's a real pleasure to be here with you, and have the opportunity to share my story.

>> EBERT: The pleasure is certainly ours. Lindsay, you clearly have been such an advocate for siblings, and as a sibling myself, I really admire the work that you're doing. I can't wait to hear more about your work, and what brought you to the world of support for siblings. To start us off, why don't you share a little bit about your sister and your relationship with her?

>> HYLAND: Sure. I have actually three sisters. My oldest sister, Elizabeth, who is two years older than me, she lives in Seattle, Washington. Then my sister Julia, she's three and a half years younger than me, and she currently lives in an AHRC community residence here on Staten Island, about 10 minutes away from me. And then our younger sister, Claire, she is four years younger than Julia, and she lives in Alexandria, Virginia. There's four of us. We live all over the place, but Julia currently lives about 10 minutes from my house now.

Growing up, Julia, who is three and a half years behind me, she was diagnosed with developmental disabilities fairly early on. She was diagnosed at around 8 months. My mom kind of had a hunch that Julia wasn't developing like my sister Elizabeth and I were at around the same age. There are benefits to being diagnosed early on.

So my parents really knew before Julia was even a year old that she was not developing. As sisters, growing up, we didn't know really what that meant. She was just our sister. She was younger than us, so she naturally was going to be developmentally under us. We really didn't recognize anything significantly different. In hindsight, I know my parents probably told us, but when we were that young -- here I am only four, Elizabeth six, Julia is one, we didn't really have any idea what that meant.

Then Claire, she's four years behind Julia, but was developing quicker than Julia, and still, we just noticed, "Okay, Julia is not responding like Claire would," and she was just different. There was no really thought about that. It was like, "Okay, she's different. She reacts differently."

We had the benefit of growing up with a really big backyard. We always would play outside. We noticed Julia wouldn't communicate the same way as Claire would respond to things, Elizabeth would. But we actually really enjoyed trying to figure Julia out growing up. We loved trying to figure out what made her laugh, what made her happy, and that's kind of what young siblings really worry about. Just, "Are you happy? What makes you happy?" That was sort of just our drive as young kids.

>> EBERT: Awesome. That sounds like a fun family. [giggling] Could you maybe discuss how some of the sibling dynamics worked with you and your older sisters, and you and Julia, and kind of what that looked like?

>> HYLAND: It's funny, I always tell parents, "Siblings are siblings. Siblings have stuff, whether there's one with a disability or not." Just sibling dynamics are very interesting. I now have two

little girls, and watching them and watching their relationship, siblings just have a unique relationship. With Jules, I think we sort of bonded as siblings over wanting to entertain Julia and care for her, and make sure she was happy. We had our typical sibling fights and sibling issues and stealing clothes and that stuff.

[LAUGHTER]

But it was really nice to have other people in the family to sort of talk about Julia, and talk about what we could do for her. There was like a mini support system going on with my siblings.

We used to have to watch Julia, just like you would watch all your siblings. I'd have to watch my little sister Claire, then it was -- Julia really needed a lot more care growing up. And even as she got older, Claire grew out of the need to be babysat or watched by her older sisters outside. But Julia never really grew out of that. Growing up, we used to have sort of Julia time where, "Okay, it's now your time. You get to go watch Julia outside." We developed that as little siblings. We had our own little unique support system, which was nice.

Growing up, I remember, we'd laugh a lot about the stuff going on with Julia. Stuff you wouldn't necessarily talk about with your other friends. But my sisters, we would really be curious about Julia together. "What's going on in her head as she's jumping up and down, and self-stimming, and do all these funny things?" I remember one time, my sisters and I were like, "Let's imitate Julia. Let's follow her for a day and try to figure out Julia. What's going on?"

I remember we'd follow her, and she loved to jump. She still does. We would jump up and down. We would flick our fingers in the light like Julia liked to do. We'd play with leaves. But after about 10 minutes, we were exhausted, and we were like, "This is exhausting trying to be Julia." It was just nice, the dynamics that we developed in our house was a very supportive one.

>> EBERT: That's great. It sounds like you guys really developed a strong bond with each other. I'm curious, you started to talk about this, but when did you guys start to realize that maybe your childhood experience was different or unique?

>> HYLAND: I think within our own house, we had our own normal. Everybody was who they were. Julia was Julia, Claire was Claire. We had what we thought was a pretty typical family. We were doing all the same things as other families were doing. But I think when Claire started to out-develop Julia, we knew that that was different. In school, I remember, when you share stories and no one is relating to you, you realize, "Okay, we've got different things going on."

Growing up, we were conditioned to realize different didn't mean bad. It just meant different. But I do remember, all my friends at school, they really loved Julia. They really adored her. She was this younger sister. She was very cute. But you realize, no one else has to worry about their siblings like I worry about Julia's happiness.

I remember that from an early age. I always worried that Julia is happy or not sick or safe. She couldn't tell us. Julia, when she was younger, she really couldn't tell us anything. She couldn't tell us she was happy. She couldn't tell us if she was sick or upset. I realize, my friends didn't have that problem, or they didn't play with their siblings the way I play with my sibling. I twirl a shoestring, and it's the biggest thing for Julia. Other siblings aren't doing that.

As we got a little older, before Julia went off to school, because she had the opportunity to go away to the May School for Children when she was nine. That was just before she went away to school that I was taking Julia for a walk, and she loved walks. She loved being outside. So if she was ever upset, I would always offer, "You want to go for a walk, Jules?" I remember my dad, he said, "Here's a dollar. Go down to the candy store down the block and get yourself a candy bar and take Jules for a walk."

Walking down the block, we go into the deli, and I get a candy bar. And Julia was someone who loved blowing bubbles. She got such a kick out of just spitting, like blowing

bubbles. It would be this long, Santa Claus-like bubble beard. I didn't mind it, because it made her happy, and anything that made her happy was something I was like, great.

We walk into the store, and this woman who was working there looks up. And she was absolutely taken aback. Looked at me and said, "Get that rabid kid out of here." There I am, I'm probably 10, maybe 11. I'm looking at her, and I'm like, "She does not have rabies. She has a developmental disability, and she likes blowing bubbles." That was my first real experience of the discrimination against Julia. I always knew she was different, and she had these disabilities, but I had yet to experience that she wouldn't be accepted for who she was.

That was a real -- I was so overcome by that moment. And I walked back and yelled at my parents. I was so upset. I was expecting them to turn around and run down to the deli and yell at this woman. But I do remember my parents saying, "You know what? She just doesn't understand people like Julia. It's important to just educate our world that not everyone is the same, and everyone is different, and everyone is unique." I just remember that was sort of the first time I really knew that I worried about Julia even more so about what her future looked like. Oh my goodness, deli people are making fun of her. That was probably when I noticed that life for Julia might be a little different.

>> EBERT: Wow, that sounds like a lot of emotional things to process for someone so young. As a sibling myself, I can certainly relate to some of those stories. How did you get through that? Are there any ways specifically that you received support that were helpful?

>> HYLAND: It's a great question. In hindsight now, I would have these conversations as I got older with my parents. When you're younger, you don't realize what was real support. When you're younger, you might just be getting the support. You don't realize where it's coming from. I always remember feeling like my parents could always help rationalize the thoughts that I had. There I was, so angry coming back from the store, and they were able to allow me to process that.

I felt like my parents, they really received a lot of support. They made sure -- they were these young parents of a child with a disability, with other children, and they made sure that they asked for help often. This is them telling me this as I was later on as an adult. When I asked them, "Why did I have so much -- what was the support I had and why did I feel so supported growing up?" It was because they went out of their way to get support as parents. They latched on to agencies. They asked a lot of questions. They always told us as kids, you have to learn to ask for help. So they did. They got a lot of support as parents.

They also made sure Julia received a lot of support. So whatever services they could find for Julia, they made sure to get her. My mom recently once told me, "We really committed to making sure that all of our children got what they needed." That might mean Julia went to respite so that Lindsay could go to ballet lessons. They really asked for help in how can I help all my children? We were fortunate to have the respites. Even my grandparents, they stepped in and offered to watch Julia when maybe we had other events going on that Julia couldn't attend.

I really think I had a lot of in-home support coming down from my parents. And also my sisters, I really feel like I had this support system with just my siblings. It's very different from parent support. I could go to my sisters and say, "I feel really embarrassed about Julia. I don't want to tell Mom and Dad. They might think I'm a bad person, that I'm embarrassed about my sister." I remember it was either one of my sisters or it was my parents, they said, "Well, you get embarrassed about me. You get embarrassed with your other sisters." So there was a lot of, "It's okay to feel frustrated about your sister," or sad or whatever it was. That really came within my own home.

>> EBERT: I love the idea of normalizing that experience for you. I think that's so insightful, too, what you mentioned about having siblings. I had brothers, other brothers growing up, so I could definitely relate to that little unit of support being built in. It sounds like you received a lot of great natural support, built-in support, while you were growing up. Could you speak maybe

more to those supports, and touch on some of the supports? Other ways that people could find support? Maybe in their communities?

>> HYLAND: When I was younger, my parents actually introduced us to something called Sib Shops. So although they recognized that we had each other, probably, I think my mom and dad wanted us to meet other kids that had siblings with disabilities. Because here they were as parents, meeting other parents of children with disabilities, and they loved meeting other parents. And my mom said, "It would be great if our daughters met other kids as well, not just within this own family."

So I went to some Sib Shops growing up. What Sib Shops are, they were created by Don Meyer. We call him the father of Sib Shops. He recently retired from the Sibling Support Project. Emily Hall is now the director. But Don Meyer recognized the need for siblings to really meet each other and realize they're not alone. They share a lot of things in common. They needed a place to share how they're feeling in a non-judgmental way.

These Sib Shops were great. You can meet other kids, and they just understood right way. You felt like you were part of a group. They had the same kind of feelings that you did. No matter what you shared, you never felt bad about sharing it. You could say, "I'm really frustrated or I'm really mad at my sister whenever she rips up my books." Because I remember Julia always loving ripping paper. You felt bad being mad at her. They were these Sib Shops which were really fabulous, and they continue today. There are Sib Shops all across the country, all across the world; and the Sibling Support Project, their goal is to train people to run these Sib Shops. We're very fortunate to have the Department of Education get on board with that, with INCLUDEnyc as well.

>> EBERT: Yay!

>> HYLAND: Yay! So we are going to have tons of Sib Shops across New York City soon. They started at a young age of 5, and they go till 12. I really think having that early-on support is really important for young sibs.

We actually have a lot of online support. There are sib groups online. One of them is Teen Sib. There's that awkward teenage stage of not really wanting to hang out with other people you don't know. But really actually loving the idea of having a place to talk to other siblings. So on Facebook, there's something called Teen Sib, and it's a great place for teens to go and hash out their thoughts.

Then we have Sib 20, so it's a group for 20-year-olds who might be starting their careers, and needing a place to share out their experiences. We also have Sib Net, which is for adult siblings who want to share stories, find out what supports are available. And then there's the Sibling Leadership Network. The Sibling Leadership Network is a national network and their goal is to support siblings across the country.

Then there's Sibs New York, which is the New York state chapter for the Sibling Leadership Network. We have a support group that meets once a month. We run a lot of meet-ups, a lot of fun meet-ups. We provide information. We provide policy information. There's actually support across the country for every stage in a sibling's life, from young to old, and it's really amazing. There is so much support out there for siblings.

>> EBERT: That's incredible. I'm so glad to know that these workshops exist, not just to support other siblings, but to spread awareness to professionals and to older adults that might be supporting siblings. I think that's a great way to provide that support, if it wasn't something that was naturally provided, or just additionally. I also love how you brought us through every stage. There's support for children, teens, young adults, older folks as well.

I know you mentioned earlier that your parents having support growing up helped you develop your own and build your own personal relationship with Julia. Would you mind talking

to us about how your relationship with Julia, or your other family members, may have changed or developed or evolved as you became an adult?

>> HYLAND: My parents, when we were younger, they really wanted us to just be Julia's sister. They wanted us to be sisters and not worry so much about decisions that needed to be made. Although they included us in that, as sisters, we really got to know Julia on a level, and we understood what made her happy. We were a family that my parents would include us in the planning, but they didn't want us to worry about it. They didn't want us to feel the need to have to become more of a caretaker for Julia. They always reiterated, "Just do your thing."

My sisters and I, we've all lived all over the place. I know sometimes making those decisions are hard when you have a sibling with a disability who needs a lot of support, and there's guilt in leaving, going off to college, living overseas. Just following your own path. My parents always said, "You're always going to be Julia's sister, and it's a beautiful relationship, but we don't want you to worry about anything else."

So there I was. I decided to go teach in England, and I taught there for three years. When I moved back, Julia had been living in the community residence she's living in now for about two years. The advocacy work my parents did to get her into this beautiful house, beautiful school programs, and they worked so hard to give Julia as independent of a life as possible, and as an enriched life as possible. And I came back, and I thought, "Wow, this is so great. Julia is going great. We're all doing great."

But I had a moment of, "Oh my goodness, I'm in my late 20s, and my parents could go poof at any moment." Although their plan was always that Julia would always be set up so that if anything happened to them, we could really still be her sister and care for her, but we wouldn't have to worry about that caretaking role. But I also said to my parents, "I really want to be more informed, because if you do go poof, I want to know what got her here, and how I can keep her here."

It wasn't that I wasn't interested in knowing all about programs and things like that, but I just didn't have to. My parents were on that role. I said, "I want to be more informed. I want to make sure that if anything happens, my sisters and I, we can keep that going. We can make sure that her quality of life is the same as it is now." So I went to my parents and I said, "I need you to sit down and do a big tree of what you did to get Julia here. What do I need to know?" My mom looked right at me and said, "You know what you need to do? You should join the Sibling Committee at AHRC. Because that will allow you the opportunity to say informed. You'll meet other siblings. It's the best way to be informed, is to be a part of this agency."

I thought that's a great idea. Really, that was the snowball to all of this other sibling world that I've entered. The Sibling Committee is a wonderful committee that provides education series to siblings. We always want to keep siblings informed of what's going on. By joining the Sibling Committee, I then was introduced to Emily Hall, who was at that stage -- she was one of the first founders of Sibs New York. So here I was, just wanting to become informed, then it sort of led me to even more siblings, and more advocacy opportunities. Which then led to the Sibling Leadership Network. I think as an adult, my interest in really helping Julia has grown.

>> EBERT: That's great. That's awesome. I love that you were talking about your development into becoming a sibling advocate. How it wasn't something you necessarily set out to do, but you just wanted to know more so that you could support Julia. It led you to all this incredible stuff. Would you say that being a sibling who advocates for their brother or sister is different than a parent advocate, or even a service provider advocate?

>> HYLAND: There are lots of layers to that question. Siblings have the longest relationship. It's even longer than a parent would have with their own children. Siblings develop a different relationship with their siblings than a parent would with their own children.

I feel like for me, in my situation, I didn't really necessarily have to worry about advocating for Julia's programs and things like that. I was advocating more for her enrichment in life growing up. But I got to know what she liked, what she didn't like. I feel like my parents were always worried about where is she going to school and where is she living. And I always worried about, "Well, she likes this and she likes this." When I was younger, I was always telling those people, "By the way, she likes playing with leaves. She likes playing with the tips of shoelaces."

So siblings, we're very passionate about making our siblings happy. Whereas a parent, although that's what they want as well, they're thinking more down the road, and where they're going. Siblings, even now, I feel like my role has changed a little bit. Because although I never used to make decisions about where I would live or what I would do prior to coming home. But now, as we're all getting older, sometimes siblings make decisions about where they're going to live, where they're going to retire, what their siblings might be doing.

>> HYLAND: That's super relatable for me also. I think that these insights you mentioned about adulthood are so helpful for the public to be aware of. I really appreciate you touching on all of this. I know you mentioned before some of the supports that are helpful for children, and you talked about some of the supports that are available. Do you want to maybe dive deeper into the supports that you have experienced as an adult? Maybe how those supports can be helpful to other adult sibs?

>> HYLAND: So Sibs New York, which is the group I co-facilitate, is the New York state chapter of the Sibling Leadership Network. The Sibling Leadership Network is this fabulous national network whose goal is to provide support for siblings. They provide siblings with information, support, the tools to advocate with their siblings with disabilities. They have conferences every two years. They are down in D.C. learning about the policies involved, how they impact our siblings.

I have found it so great to be a part of that network, mostly because I and my other friends who are siblings, we receive such a variety of support. A sibling who just really wants to get involved in policy or just information, they can find it there. Siblings who want to find support groups, they can find it there. It's really a place that has information and support for any sibling at any point in their life, at any level. It's been wonderful to be a part of that.

There are so many different siblings. They may enter into the support when they don't necessarily really need it yet. Or there are some who are in crisis mode. But either way, there is so much support. I have found that it's just so great to know that no matter what, if something happens, I have these really well-informed siblings in this network that can help me. Really, that's something I've learned growing up. That you may not know the answer, but there is some place to reach out and get help. That person might connect you with someone else, and connect you with someone else.

We have a lot of siblings in Sibs New York, and we reach out to each other. We say, "I need this support for my brother. Do you know where I can find it?" If that sibling doesn't know, we ask somewhere else. Eventually, we get to the answer to all the questions. It's just so nice to have that, which I didn't realize I would have getting into this. I have met some really amazing, wonderful people, and very well-informed people in the Sibling Leadership Network.

>> EBERT: That's incredible. I know what you mean. It can be really a daunting task to navigate these various systems for our siblings. Just having those connections, I think, is super helpful. I also know that with my experience, even meeting you, Lindsay, just the shared life experience has made a big impact on me as well. It really is just like a community, a little community of people that get you.

>> HYLAND: It's really nice to know that when you're sharing your story, other people really can relate to you. Or even if they can't necessarily fully relate, they can really appreciate what you're going through. That in itself is just really nice to have. I think sometimes people might be

afraid to reach out for help, or they may think it's not for them. What's nice is there's something for everyone. We have social meet-ups, fun meet-ups. We have support group sessions.

A lot of siblings, they become really close friends. A lot of my very close friends right now have come out of being a part of Sibs New York. I think having that common bond of having a sibling with a disability also just allows you to appreciate all the dynamics of one's life. Siblings appreciate stress (laughing).

>> EBERT: Yes, I get it, I get it. That's awesome. I really appreciate how you've touched on all the various levels of impact for siblings, and really walked us through what childhood might look like for a sibling of a person with a disability, as well as some of the adult experiences. Is there anything else in closing that you want to share with the audience?

>> HYLAND: I would like to say, if you are a parent listening, please feel free to reach out if you are thinking that you would like more support for all of your children in your family. If you are a sibling listening, we would love for you to reach out, whether to Sibs New York, or the Sibling Leadership Network. You can find us all online.

If you are a teacher or a service provider, maybe this has allowed you to think a little bit more about the siblings of the individuals that you are working with. Realizing that they also are impacted by your student with a disability. So when siblings are supported, the entire family is supported.

>> EBERT: And siblings are people who don't always think about that they need support, or they would benefit from a group like this. I'm so glad that you shared this information with us. I think it's so helpful for our audiences.

>> HYLAND: I always say that siblings...we're all in different boats, navigating the same storm. I would love your listeners to just know, especially if they are siblings, that they are not alone in this journey as sibling. If they are hesitant to reach out for support, I would hope that they did,

and especially if you're in New York, I hope to hear from you. I hope you think about joining Sibs New York, and also look into the Sibling Leadership Network. It's a really wonderful, wonderful network of siblings, and I know that no matter where you are in your need for support, you will find it, and you'll make really great friends along with it.

>> EBERT: I can definitely relate. It's like a whole new world, a new experience for siblings.

Thank you so much, Lindsay, for being here to speak with us today. I personally have learned so much from you, and the experiences that you've had. I'm sure our audience has as well. I really appreciate everyone tuning in today with us. Lindsay, thanks so much for being here.

>> HYLAND: Thank you so much.

>> EBERT: Of course.

>> HYLAND: Thanks for giving sibling support some attention.

>> EBERT: Of course. Take care, everyone. That does it for us today. Everyone stay safe.