

23 Diverse Sibling Stories

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SPEAKERS

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Chris Berstler

Welcome to the sibling Leadership Network podcast. The sibling Leadership Network is a national nonprofit whose mission is to provide siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issue is important to us and our entire families. Hello, and thank you for joining us for another episode of the SLN podcast this month in honor of National Siblings Day 2023 on April 10, we are celebrating diverse sibling stories sharing their stories with us today are Sukanya Mukherjee and Aaron Quick. Thank you for joining us today. Please tell us about yourself and what you do and what led you down your current path.



Sukanya Mukherjee 00:46

Yeah, my name is Sukanya. I currently am a consultant at Deloitte Consulting and their federal practice. And I primarily work with federal health related clients in the Washington DC area. I graduated from Babson College, it's a small liberal arts business oriented school and Wellesley, Massachusetts and 2019. And I've been at delayed ever since. What led me to kind of become a consultant in the federal government practices, really, because I've always kind of been passionate about creating an impact and helping others and I was really drawn to social impact consulting and thought it would be a good way for me to have a role where I could make some money and also, you know, help folks and kind of do something mission oriented. And I think a lot of that kind of nature does come from me growing up with my siblings. So for me, yeah, I definitely like have always kind of gravitated towards jobs where I could help others in some sort of way.



Aaron Quick 01:46

Cool. All right, I guess I'll go. Yes, my name is Aaron quick, he him pronouns. So currently, I am a full time doctoral student at Clark Atlanta University in Atlanta, Georgia. My background is social work. And so I have my bachelor's in Social Work from Central State University, and Wilberforce Ohio and HBCU. And then I got my master's, this past May, at North Carolina State

University. And so I've kind of gone all the way through, I've never stopped when it comes to education, you know, 25. And I was like, Hey, let's just go on and get another degree. I've started doing that my very focus in my PhD is looking at the mental health of law enforcement, and specifically how a lack of mental health intervention for law enforcement officers is leading to police brutality. And so a big reason why that kind of that became my interest is because of 2020. Because of the protests, I've done a lot of internships in many different areas regarding policy analysis and Social Policy and Social Justice. And so after what we saw, in 2020, with protests after the death of George Floyd, Breonna, Taylor, all these, you know, people of color, and being in a lot of the communities that I've been in, whether it's working at, you know, LGBT centers, whether it's working at domestic violence centers, working with people with intellectual developmental disabilities, just during my social work career, all these communities have been impacted in some way, shape or form by police violence. And so I realized that I had to stop looking at it from one specific lanes of just racism and understanding what are the actual causes the causation that leads to police brutality. And so I tend to use a interest conversion framework, which means I'm trying to take the interest of the community and what it is in the diverse communities that are looking to end this social issue. And then I've also worked in police department, and so also understanding their perspective to come to a convergence of interest so that we can really solve this issue. And so that's what my PhD kind of focuses around. It centers around. I'm right now working with the Georgia Council on Developmental Disabilities, specifically as their public policy fellow. And we're looking at, you know, policies and things that are being introduced in regards to Georgia legislation that impact that community. And so, how my career trajectory and where I am as a fellow kind of merged is understanding the policy realm, understanding legislation, and how it impacts specifically marginalized and underserved communities is vital, even though we do the grassroots grassroots work, understanding that policy on that macro level impacts everything influences everything, and so having to get an understanding have that as someone who one day wants to run for office and be in Congress, I have to, I really want to grasp the ins and outs. And as my supervisor always tells me the game of politics. And so that's where I am right now. I'm really, it's a full of amazing opportunities. And not to only, you know, advocate for myself, as I said, but also really just be the microphone that allows those with the everyday experiences, to really make sure that their voices is heard or heard. It's awesome. So that's a little bit about me.

C

Chris Berstler

Tell us about your siblings and what your relationship was like growing up and how your relationship is now.

A

Aaron Quick 05:45

My brother, he is actually my older brother, he's actually turning 29 Tomorrow, it's a we're planning his party. So don't say anything. So yeah, we're in the midst of planning his party, and we're getting him getting him a cake. Yeah, my my older brother Ryan, he is an individual who lives with autism. You know, growing up, I think it's, it's very interesting, specifically, being in a POC household, we didn't have a lot of knowledge on understanding, you know, what I appreciate about the relationship between, you know, just as a family unit, my family is that we've had many conversations in regards to how do we best navigate, understanding that the needs of my brother Ryan are different than, you know, me, I have two older brothers Ryan,

and then my oldest brother, his name is Trey, like, it's different. Our needs as me and Trey is different than Ryan's needs. And so how do we navigate that, and I think, you know, growing up as a younger brother, it was kind of hard for me to understand. It was hard for me to kind of that's just, you know, immaturity, like, you know, he's my older brother. So I should, he should be taking care of me. And there were times where it's like urine urine jars. And it felt like and so that role reversal was awkward for me at time for me to understand. And I think it really was growing up and being really starting my my social work career and being exposed and really understanding what it means to be an individual who lives with an intellectual or even a developmental disability, I really began to understand by doing that self work that self interested, you know, just reflecting on self and in growing my competency in so yeah, it definitely was a learning curve. But it wasn't just for me, it was for my entire family. It's not just us learning, but then you have to teach grandparents who don't know much about it either. And then you have to teach aunts and uncles in when we go to family reunions. And, you know, as just as you know, we evolve. So do they are siblings, and sometimes the things that trigger them, or that set them off, change in shift and adjust, or they are one day, they're not talking the next day, they are talking and they're like singing and dancing. And so it's, it's that constant having to learn, even though I know he's my brother who lives with autism, that is not normally how I introduce him, he's just my brother. Like, in so it's really interesting, because even this identity of being a sieve is new to me, you know, within like, the last couple of years, because it's not, it's never been something that I've used, even when I've interacted with other people who have siblings who have an intellectual developmental disability, it's never been like, I've never identified as someone like, yeah, I've a sibling who has an intellectual disability. No, it's just my brother, he navigates the world different. Lee then just like as we all navigate the world and the way we navigate this world. And so yeah, it growing up. It just was different. You know, it was different experiences, like there just were highs or lows, there were times where we're seeing great growth. And then there were times where we had to, you know, take him to a special facility to get him the assistance that he needed. And again, it can be scary, and you're not understanding what's going on. And, you know, even as parents who've never had to do this, and the conversations we've had, they've been like, we didn't really know what we were doing either. Because just like, parenting is not there's no handbook, you know, it there's no correct way or wrong way. It's just you're doing the absolute best that you can. And so I think, you know, the biggest thing that I've learned Aren't the biggest advice that I give to people as they're navigating the process. First of all, it's a lifelong process. And let love and let your connection as a family kind of be that foundation. And when that's the foundation, and you know that you're always doing your best, that's what that's what that's what matters. And so, you know, lots of experiences, lots of areas for growth, and continuing to grow. And at the end of the day, it's just always about, you know, loving, you know, your sibling, loving your family, and always just trying to do the absolute best that you can, you can't really ask for anything more than that and into to do your best. And so yeah, that's, that's a little bit about my experience growing up.

5

Sukanya Mukherjee 10:46

Thanks so much, Aaron. So for me, I resonated with how you, you are like the younger sibling and I am as well, my daughter is 13 years older than me, her. And she like, her name is Jim Moore. And she was born, you know, again, like 13 years before I was born. So kind of she was had her first couple years into this life without kind of me even being there. And I think a lot of that time was spent abroad, like they, my parents had her in India and then moved to England and Scotland actually to give her better care and the disabilities that she has include deafness, developmental delay, and autism as well. But I think her circumstances are really tied to having

she I guess she's like, she's she was born with cognitive rubella syndrome, which is where my mom had German measles when she was pregnant with her. So the, the, I guess, intellectual developmental disabilities that caught our occur because of that are not often like, labeled as like, autism, or like clear developmental terms, but they like, take on those her behaviors and actions take on those types of like, forms, essentially. But I think her kind of main challenge that I've kind of seen, you know, as I kind of came into the world, and we moved, you know, they moved to the US, like, around the time I was born, was really like just watching her, her early years, just being really struggling to engage with the world. And I think for her, it's really challenging because her deafness, prevents her from engaging with the speaking world. But then her intellectual disabilities prevent her from engaging fully in the Deaf culture as well. So there is isolation, I think, from both sides. And of course, I think she definitely resonates the most with deaf culture. But you can see, even within Deaf culture, it's, you know, we have to be very vigilant, because she could be taken advantage of she's more naive and just unaware. And she doesn't have the same cognitive functions as, you know, normal, able bodied folks who just happen to also be deaf, but you know, everything else, cognitive blue eyes, their functioning, kind of just like you and me. So there is a difference there. And it's hard to watch that, I think, and because of her intellectual disabilities, her learning ability is stunted. In that, like, she's not just able to kind of pick up what she doesn't know. And her like, reading abilities sounded so definitely challenging there. And I think, for me, growing up, I really did kind of feel the role reversal. So I like from a very young age, I think I felt like I was the older sibling. And I, it's, you know, I don't think I've ever felt as though like she took care of me. So I definitely, like see her as my sister. But it's actually like interesting because I don't really think of her as my older sister. And I think it's hard for me to like think about it that way because of the relationship that we've had. But I remember kind of growing up and just watching like how much you know, my parents really sacrificed for her, you know, leaving their home country. Also just like spending so much time with her outside of her she would absolutely have her like schooling activities to try to help her learn how to read more and like try to get her involved in different like sign language classes or like taking her to Starbucks so she can mingle with other deaf, ended up mingle with others and the deaf community. And just kind of watching that has always been really phenomenal to me, but I think, you know, growing up of course, they're like, similar to you like there were highs and lows, so I feel like I felt oftentimes embarrassed. I didn't I understand what was really going on. And she, I think, was also struggling a lot during those early years with depression, anxiety. So, you know, her mood would fluctuate, and I think it was hard for me to just fully understand, like, you know, I see that she's kind of in pain or in suffering, but I really can't comprehend like what to do about it, per se. And because I was the only other sibling I didn't have a lot of like people to turn to, and definitely grew up kind of feeling a little lonely a little, like, just confused. And as I grew older, I joined I remember, like the first inkling of like me feeling like, oh, there's like other people that could start to relate with me this is when I joined. Like, it was similar to like a Best Buddies club in high school. And we called it my friend and I, and there were other students there with intellectual and developmental disabilities. And it was really my first time meeting anyone who had intellectual and developmental disabilities outside of my sister. So that was just really helpful to see people in that those communities and like how I could help them and that also encouraged me to, like, you know, sit with my sister more and help her how to read and like, you know, started to spend more time with her and we have our own type of relationship, right? Like it's a really more silly loving, kind of nurturing relationship rather than like a like, here, let me help you with your homework and that type of thing, like you may expect from a normal like a older sister, younger sister relationship. But yeah, that was kind of like what it was like for me growing up. And as I kind of went through high school, I definitely did want to kind of have a more independent college experience. I think part of that definitely drove my decision to like move from California to Boston and and just also just wanted to get some like independence

from like, what, what, what, who am I kind of outside of this, like family unit. And now I think, you know, I'm like, three, four years out of college, I spent, actually like my last semester, or last year in college writing a memoir about my relationship with my sister, because I think there was so much for me to process. And I remember, like, I was in the Honors Program, I school. And basically, you could write about anything, and I like have always wanted to write about, like, my relationship with my sister, and like, what that looked like, and how my parents have really, like poured their livelihoods and to like, helping her. And it was really healing for me to write that and try to, like, explore just what it was like to grow up and know that, you know, you Aren't your parents first priority and like, like, what does it look like to kind of be in that role. And I remember actually, like coming across the sibling Leadership Network, because I wanted to hear from other siblings, like what they felt and like, you know, if they felt similarly, and I think the first time I like noticed that the sibling is often kind of ignored is when social workers would come to our house, you know, yearly, or like, in doing kind of checkpoints to see like, oh, is your like, is she getting the care that she needs? Like, you know, are there any job opportunities for her and they would always, like, speak to both of my parents, but they would never really be interested in speaking to me, because I'm just not part of their like checklist. And it's not really important for them. And I always wondered, like, why not? Like, I kind of see everything that they see, like that my parents see, like, you know, why not talk to me. And it was just started to kind of be fascinating for me, like, okay, like this role of the sibling is kind of absent from this narrative. So let me explore this. And it was really cool to just kind of be a part of the Facebook groups that were there and just hear how people were kind of dealing with their own unique journeys and challenges with well being ACIP. So I would say like, my relationship now is a lot stronger, only. Partially because I've done like, a lot of reflection on it, I, you know, have spent a lot of time at home to out during the pandemic and move back. And it's just been nice to see, like my sister grow as well. And like, like, like you were mentioning, they evolve as well. And like, now, she has been able to pick up a lot more things and we found a really good program for her in our local community college. That's for deaf individuals who have intellectual disabilities, and like, you know, finding that niche within a larger community I think is so critical for helping her get the the care and support that she needs. And then you know, watching her make friends and seeing her like, the happy because of those like circumstances. It's just been so kind of rewarding to watch. And I think as she grows older, like our relationship gets better too. So it's, I think it's been good and on an upward trend. And I think what I really am thinking about now is like, you know, what does the future look like and I think one of the reasons I joined more of the leadership type of roles in the sibling leadership community is I'd love to hear from like a other people, you know, my age adults now like, what does it look like for you to care for your sibling? Like, what are the options out there? And I think similar to you, I don't, I don't think my family had a ton of information just given, you know, you have to kind of seek it all out yourself. And I think almost every sibling, like this type of family unit can relate to that. So it's definitely something that I'm like continuing to explore.

A

Aaron Quick 20:27

Yeah. And I kind of want to just, you know, add on to what, what you were saying? I think it is. And I think sometimes it's hard to, it's, it can be difficult to say, because it almost feels like you're being selfish. But there is a sense with typically, when you are the the younger sibling, other said that you feel like you were kind of neglected, or felt like you were never given the the attention that you wanted growing up, because your parents had some focus so much on your sibling. And it's not until you're older that you realize that. I get it now, like you said after that self reflection, but I think there's still, I think that does speak to even as, you know, resources and care whether it's social workers counseling, whatever the case may be, is being

provided to your to your sibling, and even, you know, classes given to your parents. other siblings should also be included in that, because there are valid feelings of feeling not just, I don't even understand what's going on, just because of my cognitive like, I just, I don't like not even included in the narrative. Like your opinion is not important. Absolutely. I mean, there are many times where you know, something's going on in my life, and I you go to your parent, but because, you know, your your siblings have been activated by something or going through, and your parents like, we cannot, we can't do this with you right now. Okay, go do your homework go, right. I don't care. That's what Sal said this to you at school, I need to focus on your brother, or focus on you know, your sibling, your sister, whatever the case may be. And, and you feel like man, not only do I not understand what's going on, but I don't understand why I'm not getting any attention either. And so I think that is a, it's a valid feeling, and something that you have to work through, specifically, because you can start forming resentment towards your sibling for something that of course, they cannot control. And of course, you know, it's never purposeful, by your parents, either, specifically, those who do not have adequate resources, they're simply doing the best that they can. And so it really is, I think that is, I would imagine that that is a shared feeling. And even a feeling that as you grew up, and as you start to realize this, like, Man, I feel kind of bad for real in that way or, but I still think that is a valid feeling that, that that, you know, caseworkers, social workers who are working with families that have an individual with a developmental or intellectual disability to also take note of, and that's coming from, like someone in the field. So but but yeah, I just wanted to validate what you were saying.

S

Sukanya Mukherjee 23:22

Thank you. And I guess just to add on quickly, like, I think, um, I think it also starts, I don't know, if you felt this way, but I feel like it shapes my personality, and that I like, started to feel bad to bother my parents. So I would, you know, like, my, like, educational style was to like, okay, like, let me do the best that I can so that they don't have to like worry about my grades or how I'm doing in school, like, let me just do everything the way that it's supposed to be. So there's like no reason for them to come in, and like really monitoring me. So I think that's like, it's really part of my personality, like, even at work. I think when I'm like dealing with my manager, I'm kind of like operating in a way where like, I will kind of make it so that you don't really have to manage me and I can like do everything independently and like you can come in and I can show you things but like I will kind of operate independently. And I think a lot of that comes from like, this feeling of like, okay, like, I don't think I can really go to them for support, because they're so overwhelmed and you feel like you want to protect them in a way or at least I did. And so you just like start to like overcompensate for it.

A

Aaron Quick 24:40

No, I definitely agree. I think specifically in my case, what it became was, I already expect you not to be able to be there for me and so I have to take care of it myself. Right. I have to like I'm gonna get it done myself. It's never to say that my parents you know, we're Never there. But I understood, like, if I need to get something done, I need to do it myself, I think that has had an effect on me because even now, it's difficult for me to let people do things for me. Yeah, because I'm so used to doing it myself, which I have to learn very quickly that I can't do that, because I will burn out very quickly. And sometimes it's okay to be like, submissive, so to say, not inlet, somebody helped me in let someone you know, they see that you're struggling. And

so let me assist you. In so in I've had to learn through my own self reflection, that many that's kind of stemmed from that, like, growing up so quickly and learning like, Oh, it's so crazy. Because even now when when big things happen, like whether it's like, you know, being in the Honor Society getting a big scholarship, I just wouldn't tell my parents, because I you don't have time, so I'm just not gonna tell you. And that that has definitely changed over the years, but it was just like, you know, yep, I'm doing good. I'm doing, you know, doing great things. But it's like, I don't know if you'll have time, so I'm just gonna bring it up. But yeah, I definitely, I definitely hear what you're saying.

C

Chris Berstler

How has being a person of color impacted your sibling journey?

S

Sukanya Mukherjee 26:28

So I think for me, be kind of identifying as an Indian American, has shaped our family, I think, in that, originally, like, when, you know, when my parents and my sister, like, came from India, I think my mom and dad faced a lot of social stigma, I think, you know, before I was even born, that I think it's definitely like, impacted their perception on and how welcoming, they think people will be of my sister. And I think you know, even in the US, they are really hesitant to really open up about their experience with her. And you know, they'll do kind of, they'll have, they'll take leaps and bounds to help her connect with others, but they rarely, I rarely see them kind of make friends with with others and try to like, kind of share and these types of conversations, because I think a lot of like stigma is in their minds of like what someone will say about our situation. So I think that really shapes it, because I don't think that they feel like they see it being normalized in the South Asian culture of what it looks like to have an individual with intellectual or developmental disabilities, and then they don't know how to navigate this conversation. And they don't know how to find those people. So for me, I think how that translated is that I personally just grew up in a, I grew up in a very east Asian part of in a suburb in Los Angeles. And I think I was really, like, eager and open to make friends with anyone, but I would not really talk about my sister at all, until much later in my life where I felt more comfortable opening up and kind of being honest about like, my, who I am and how she is a part of my identity. So I think that's really how I think like, culturally that's shaped a little bit of it. And I think, I don't know if like, if I was a part of if I identified as a different ethnicity or race, if there are more resources in a particular ethnic or racial like, makeup. I don't know if that's true, but I don't know if they would have shaped my experience differently. But I just know, like for me, in the South Asian community, like I don't really see it talked about really at all. And it could be that I just don't really like know how to find those resources too.

A

Aaron Quick 29:13

Yeah, I definitely would say, if anything, I don't know if being a person of color of being black African American, really impacted our experience. Truly, you know, on a just like, really in our face like we experienced difficulty simply because of our you know, because of our background. I think many times the the issues are lack I kind of mentioned before, kind of like internal within the community. So just a lack of knowledge within black communities or just communities of color have definitely allowed stigmas to perpetuate themselves. and be reiterated, and I think

also growing up in a religious household, just prayed away, like those things also have an impact on people believing like, let's just pray for it, or you'll get over it just like many different identities. It's certain of you that need that people face, you know, we can just go to temple go to church, it'll be fine. Like, we can just kind of ignore it, because we don't understand it. So we ignore what we don't understand. Just like sometimes we fear what we don't understand. There were times where people just did not want to understand and then there are times where people overcompensate, like, you don't have to talk to him really slow, like he can, he can convert, you know what I mean? Like just overcompensating? Or don't do baby talk, like, why are we doing that? That's not what you need to do. And so I think many times, it's less about, you know, the color of my skin, just people, they're, they're ill informed their own ignorance. In many times in specific communities, ignorance that's been allowed to kind of continue on, in a lack of information has played a much bigger part. In our overall experience.

C

Chris Berstler

When was the first time you met another sib? And how did it make you feel?

A

Aaron Quick 31:23

I can't remember the first time that I actually, you know, you interact with people who also have siblings who have intellectual developmental disabilities. But again, it's not like I kind of like, harped on it or like, oh, my gosh, we have this in common. Like it was it was never like that. So it was never something that was really stuck in my brain. And I don't feel like when I got to a place where I could acknowledge, oh, my gosh, we do have that in common. That is something that made me feel any type of way. Because by that time, I know I don't look at, like I said, my sibling, or even others with individual intellectual or developmental disabilities, do a deficit land. And so I'm like, Oh, you just have a sibling. Like, if we talk about our experiences, we'll talk about our experiences, just like people with diverse backgrounds or experiences, talk about their experiences. I feel like the first couple of people that I've met, it wasn't even something that we had, like, you know, heart to heart conversation about it, it was one of those like them passing like, oh, you know, my brother's a, you know, because my brother is like, a, an author. And he's written a children's book and gotten awards for and I bring it up, and I'm, like, oh, my gosh, that's so crazy. Yeah, it's really, really cool. And all these kinds of things. And then I'll bring up the point that, you know, it's even more amazing, because he lives with autism. And, you know, it's like, oh, my gosh, my sibling, bla bla bla, so we talk about it. And so it's just like, it's just like hyping up your sibling. That's all I'm doing. It's not because of the, you know, intellectual disability he lives with. It's just because he's my sibling. And I think he's awesome. And he's doing things because I never date. Right. No book. I, you know, I just read up. So, you know, and I definitely haven't won any award. It's, it really is. I never really harped on it like that. And so, you know, it's, I don't know.

S

Sukanya Mukherjee 33:29

For me, it was a little different, because I think, um, I like just, I really wanted to meet someone who is similar to me, and I just felt like no one could understand where I'm coming from. And there was a little bit of jealousy for me. I know, like growing up, because I would watch my other friends who had older siblings. And they would like take them out to the movies, and

they'd be like, Oh, my older sister took me shopping and like, you know, just like things that like I would want to do. And I just like don't have anyone to do that with Are they really going? Well, my older sister like shared the story about fruit to me about like, what happens in high school and like when ordering when middle school and I just, you know, don't have those like conceptual things to compare to. But I think the first time for me when I met my older sibling was was on on Facebook, through the sibling subnet, like Facebook group. And I think I just like responded to someone's post and they were going through a rough time. And I kind of was just like, hey, I kind of like resonate with this like, you know, I hope you're feeling okay. And they messaged me and like, we just like talked for a little bit like online and it was just really that one day but I remember feeling really surprised that like, I could connect with a stranger who I've never met before in real life, but I'm just off of that experience and kind of like give them comfort during that time. And I thought that was something really unique and rare. especially about the sibling community that like you just have this, you know, if you choose to talk about it, you do have a shared experience that not everyone who's who's not ACIP can really just understand. And that shared understanding often allows you to just be supportive of one another in a way that like others just gives can't be. So that was my experience,

C

Chris Berstler

In what ways positively or negatively did the pandemic impact your relationship with your siblings?

A

Aaron Quick 35:32

So definitely, during the, during the pandemic, during the start of the pandemic, I actually was getting my master's. And so my parents were here in Atlanta, and I was in North Carolina, definitely, that is where a level of my self introspection kind of started in just reflecting on growth. And because that was the first real time of course, during my my Bachelor's, I was away. But this was the real time it was on my own paying for my own place, all that all that stuff that I that I really was able to sit in my own four walls, and just kind of reflect on life, reflect on my family, reflect on my relationship with my brother. And that's where a lot of growth happened for me. So that actually, once the pandemic was over, I actually, in I finished my degree I, I moved back home. And it was amazing to just see how it really is that time a way to really sit and reflect, allowed things allowed me to find my own healing and find my own growth so that when I come back, I'm really able to continue to build on that foundation. And ask for forgiveness for things that need to ask for forgiveness for, and really strengthen our relationship. And that's really what happened, our relationship grew. As my sibling also grew, as my parents also grew, as my, my other brother also grew. And so when we came back together, it was actually really amazing how, just sometimes that that time apart, really is beneficial. But when you come back together, and you can say, Yeah, you know what I said, and when I did, and my lack of understanding, I think I've really grown. And it was amazing, because we started like having family meetings weekly. And just checking in talking about where we are, how we're growing all that different stuff. And so yeah, and so I think that that was definitely something that really was amazing, I think, unfortunately on on a negative note, what kind of end up happening because of the pain panic. My my brother developed, you know, a fear of germs. And so now, we're working through that. Because now he like washes his hands to his skin rubbing off. And so it's like, okay, so when I talk about, it's a constantly, it's evolving. Okay, so now how do we, how do we work through this, and I think the most difficult

part that we experience as a family is that he's very high functioning. That's just because of the work that we've done. And the hardest thing was when he said, I don't want to feel this way anymore. And so I don't want to be afraid of germs. And yet I am and to hear that you're struggling, and we're trying to work through it. Is that difficult, and we have to sit with that as a family, we have to talk to a family therapist and be like, how do we let us know that I don't want to live with this. And yet I am how do we navigate this? How do we work through this? Are we doing something wrong? And so even with the growth, there comes new challenges that you have to now work through with this new growth that you've that you've earned, that you've, you know, garnered, and so, you know, the pandemic, just like all stages of life, ups and downs, ups and downs. But when, you know, like I said, our connection our love is the foundation. It's helping us work through that. And it's getting better every single day. But yeah, with with life comes different curveballs that are that are thrown at you.

S

Sukanya Mukherjee 39:30

Yeah, for me, the pandemic I was home for like half of it. And then the good second half, I was home like basically like, end of 2020 onward. And I know like while I was away I was in DC I know I was hearing from my parents just how difficult it was for her to just be kind of taken out of the environments that she was used to like she could no longer see the friends that she'd made at Starbucks, or she couldn't go to school for an hour anymore. Like it turned into remote online learning. And that was a challenge for her initially. And I think, you know, it was a challenge for my parents too. And similarly, she was really scared of COVID. Because I think she just, you know, didn't understand it really well. And, you know, people are telling her, like, you have to wear a mask and like, you could catch it. And she's like, Oh, how do I know if I'm gonna catch it? And it's like, I think it's really so hard to kind of explain those more complicated topics. And it's like, I think sometimes they, like my sister will just kind of take it for what it is right? Like, okay, you're telling me it's a virus, so I can't catch it. So like, do I stay inside all the time, and it's hard for her to see the shades of grey. So definitely, I kind of resonate with what you're saying. And then. But overall, I think like the pandemic, didn't, you know, I think she was really happy when the pandemic started to ease up because she was able to, like, go out in her circles again. And I think that just kind of goes to say that, like, the pandemic for her, like those communities, I think created isolation, especially for folks who really just, like, thrive on like, being in person together and having those experiences. It was really challenging, I think, and even like, having smaller social distancing gatherings, I think was tough, because she doesn't know those, those people that well, and she doesn't know like, how to navigate those kind of questions that maybe you and Iran asked like, okay, like, you know, have you gotten tested recently, or like, you know, and you said, Okay, we're only kind of mingling with each other. So it's, it's almost easier to kind of be like, I think, you know, you have to kind of stay isolated for until we know that it's kind of safe for you to go out. And I think there's also like a heightened level of concern to about her health, because she's not able to communicate and express that how she's feeling. So if she were to get sick, there was always this kind of concern, like, okay, is she going to be able to communicate, she's really feeling to make sure that she's getting the care that she needs. So definitely some like fear associated with that. But, um, yeah, I would say like, overall, like, it was a learning experience for her to, like, get used to remote learning, and like, what that looked like, and she learned how to kind of use PowerPoint and Excel along the way. And like, now, she makes me like birthday cards and PowerPoint, and it's really cute. And like, I think, like, those were, like, skills that she learned kind of being, like, forced to be at home at home, and like, kind of start to like, make use of the situation. So definitely some

positives, but definitely, I think overall, it was challenging. And she's she's so happy to be back, you know, at school and things like that now, so I think, better that it's, it's kind of easing up for everyone, I'm sure.

C

Chris Berstler

What are your hopes for the future of the sibling community?

S

Sukanya Mukherjee 43:14

For me, I would love to see more information and resources being shared. I think it's so critical to share like these stories, too. But it's also just as critical to share maybe like tactical information. And I think, you know, we are all so busy. And I think a lot of the work that we do is you know, volunteering, and we're trying to do what we can I just I think I wish that there were like resources where I could kind of, like if I live in a state, you know, live in state of California, like what are the resources available, like in a centralized place, like, for depending on the type of disability that your sibling house, like, what should you do? And like, that type of database, of course, will take so much time and effort to build but I think, you know, in an ideal world, I think that would be fantastic. Because I think families want to figure things out, you know, but with with the resources they have and they want to be able to be self sufficient looked things up. And it's just can be hard when there's just not as much centralized reliable information out there. And you're kind of having to cobble together everything and I think almost every family runs into the situation where they're needing to do that.

A

Aaron Quick 44:27

Yeah, I would, I would definitely agree on on resources. In in specific, I would say even specifically resources for the some of the more like nuanced things that individuals with intellectual and developmental disabilities experience so like, for example, right now, my my brother, he's vocalizing that like, I want to be married. I want to have kids. I want to move out the house. I I want that And so that's a whole conversation in, in, in how to we then navigate helping are helping to make that happen. Finding a partner, you know, he's getting to the point where he no longer wants to be, you know, the dependent of my parents. And so like, Okay, you're Wow. Okay, so how will we how are we going to navigate that? How are we going to, you know, what are steps for that, and then you realize there's no resource to help you to navigate that there's, well, there's resources to make sure, you know, jobs and, you know, other forms of being independent, but something like relationship, and then how do we, whoever is the other, you know, his partner, like having a conversation with, you know, their parents, and here it is, you know, he's 29 years old, and we're doing that, is that awkward? Should we be doing that? So, it's, that's a whole different ballgame than what we were working with, you know, five, two years ago. These are the, I think some of the little things that are kind of like, not even thought about. And once it kind of happens, you're like, we don't know how to go about this. And so yeah, I think resources are always going to be something that we want to see evolving and being more readily available. And just even on those little, little things that are that, you know, people with intellectual developmental disabilities want to experience just like the rest of us. But I definitely agree more resources, and specifically, more resources for siblings at a younger age, and helping them navigate it, and helping them understand it more. Helping parents teach

their, their, their their other children, how to navigate it, and how to understand it more. All things that I think are necessary, and I think will make the experience. I don't think, you know, easier isn't not the word I want to say. But just helping our competency, even from our younger age, and how do we talk about it? How do we, you know, understand it, I think it's very important. So I would love to see that.

C

Chris Berstler

Finally, do you have any plans to celebrate National Siblings Day this year?

A

Aaron Quick 47:38

Yeah, I'll be straight up honest. Like, I didn't know the thing. That now like, like, when I saw the question, I was like, Wait, we're gonna do a little Google search? Because I was like, Yes, save honestly. So I'm playing. Now he's gonna get this party tomorrow. And it's about to be awesome. So I'm looking forward to that. But I think now that has come to my attention. You know, me, me and my two siblings. I mean, we're very close, like, We talk all the time, even though he's getting ready to move to Mexico. But yeah, my oldest brother. But we're very, we're very close. And so I've definitely now that I know, I definitely, even if it's something as simple as sending them a text, like in our own group, our little group texts, like, I love you. And, you know, we have all our little baby pictures together, just stating that, you know, that's always it's just the little thing sometimes. And I guarantee you, like, there's no way by my older brother, who you don't know about every day, but he's gonna know about it this year. I actually put it on my on my calendar. And so it's like, hey, just send them a quick little text to let them know that you know, you're thinking about them.

S

Sukanya Mukherjee 48:58

Yeah, no, same. I didn't actually, like fully know about it. I think it's probably something where, like, every other year or something, if I go on Facebook on that day, maybe I'll see like posts about it, but I don't even go on Facebook anymore. So like, I don't know, um, but I think you're right. Yeah. And that like, if I actually like my sister loves, like, sharing any message that she can for any holiday. You know, it's really big for her like, Merry Christmas, Happy New Year, Happy Fourth of July, like she's got us send a message on the holiday. So my teacher this holiday, I think she will be enthusiastically sending me a message. So I should send her one as well. And I can introduce it to her. So I think that that'd be a nice thing to do. But you know, I think of course, like we should, we should really treat every day as like a day to really appreciate her siblings. So yeah, I don't nothing like a special per se but we'd love to like, share that with her too.

C

Chris Berstler

Thank you so much for sharing your stories with the SLN audience today. I really appreciate it and I think siblings out there, will get a lot out of it. So thank you so much for your time. Any resources that were mentioned you can find in the description below. And we hope that you and your siblings have a very Happy National Siblings Day on April 10. Thank you. Find

resources, tools and information about the sibling experience on sibling leadership dot for the sibling Leadership Network is a nonprofit, and we rely on support from our audience. Find the donation button on our homepage and contribute to the ever growing sibling movement.