

24 Sib-In-Laws

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SPEAKERS

Chris Berstler, Sumithra Murthy, Cory Hartman

- C** 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 in our entire families. Hello, and thank you for joining us for another episode of the sibling Leadership Network Podcast. Today we will be talking about seven laws. I am joined by seven laws Corey Hartman and Sumi Thoreau. Murthy, thank you so much for joining us today.
- C** Cory Hartman 00:36
Thank you for having me. Sure.
- S** Sumithra Murthy 00:38
It's a pleasure. So
- C** Chris Berstler
I'd like to kick things off and just ask you to please tell us about yourself and how you came to be ACIP in law.
- S** Sumithra Murthy 00:46
So I'm Sumithra Murthy, and I'm the visiting clinical assistant professor at the Department of Disability and Human Development at the University of Illinois at Chicago. I'm from India, and I've been married for more than 27 years now. So my husband's sister, my sister in law is an

individual with intellectual disability. And I think that's how, like, in India, you know, I knew my husband before my wedding. So I knew that he had a sister with intellectual disability. So I was kind of prepared, when I went into the family that I would have these experiences with my seventh law, I think that's a brief introduction about me and how I came to be a civil law.

C Cory Hartman 01:35

So my name is Cory Harmon, I am a director of safety and security. I am 35 years old and have three amazing girls age 1715 and four, before me and my wife and getting married in June of 2017. I really didn't have much interactions with those with disabilities except, you know, in minor situations. So, when meeting my wife, she told me about having baggage and I said, Well, I have an ex wife and two kids. So we all have baggage, and she said, Well, mine's a little different. My sister has developmental disabilities as well. And I'm like, okay, you know, that doesn't make us or break us and who we are. So that's how I became involved. In this similar role,

C Chris Berstler

in your own words, what's it like to be a seventh law, please share any challenges or benefits you experience?

S Sumithra Murthy 02:31

My sister in law lives in India with my mother in law right now. And my mother in law is almost 78 years old, as her primary caregiver. My father in law passed away in 2007. And my husband doesn't have any other siblings. So you see, because of the lack of future planning options in India, my husband and I do understand that we would be the potential future caregivers. So one of the major challenges is to unit what would happen to my sister in law, you know, after my mother in law, you know, getting a residency status here would be a great challenge. My sister in law has multiple comorbidities and has many health challenges as well. She used to actually attend a day program at the National Institute on empowerment of persons with intellectual disabilities in India, where they live. And that's a National Institute, specifically for people with intellectual disabilities and other developmental disabilities. But because of COVID, she has not been attending the program since 2020. You know, these are some of the challenges that I see. I think it was very isolating for my mother in law and my sister in law during this COVID times. And that kind of makes us think, you know, what will happen later, and we all understand long COVID And we all understand that people with comorbidities are affected. And they both get COVID at some point of time, and they do experience some long COVID symptoms as well. So it's really scary for us thinking about the future of my sister in law, especially because of, you know, lack of future planning opportunities in India, and my husband being the only sibling, like what would happen to her later and we are thinking of ways to kind of make sure that she lives with with us in some capacity. We are going to be her future caregivers and the only caregivers. So that is definitely a challenge. And we are trying to navigate and looking for options, but to really look at the benefits. My sister in law, she provides companionship to my mother in law helps with her household chores. Words, and she's very affectionate, and with, you know, my mother in law and other relatives, so she provides a lot of such positive benefits, like my mother in law is scared to live alone. So you

know, she's a great support to my mother in law. So that way it has, it's a very rewarding relationship. And sometimes my husband, and I feel that, you know, because my sister in law is still living with my mother in law and providing that support, we are less worried about them right now. So that's a huge benefit.

C Cory Hartman 05:35

So just I mean, we deal with the same thing, the future planning, even United States is not the easiest thing. My mother in law is with my sister in law, they live together 24/7 365, my sister in law does not as long as I've known her, go to any programs, she wants to be with a mother takes care of her mother. So we run into the same issues, long term planning, estate planning, and things of that nature. My wife's father, is someone that we love very dearly, but would not allow our sister in law to live with just because of their nature of their relationship. One of the best benefits I find is that my sister was very honest with me, very honest with me, we have her over for dinner, she will turn to Me, your past has not cooked enough. Can you know, and it just that overwhelming, the honesty part. And she'll say if she's happy and sad, but I also think that the biggest relationship I love to watch is with him and my four year old daughter, they just have that bond and connectivity, but also very worrisome, and becomes a challenge. Later on. We'll talk about why because when my daughter starts to read, it's always well, why can't my aunt read? Why can I do this? And that? So it's also navigating some of those different challenges in life?

C Chris Berstler

What are the biggest ways your life has changed since becoming a seventh law?

S Sumithra Murthy 07:08

That's a great question, Chris. Well, my life definitely has changed a lot. You know, first of all, I would just like to kind of tell you a little bit about my background. So I studied medicine in India and became a physician. But despite that, you know, I never understood the lived experiences of living with a person with intellectual disability, like how Cory mentioned before, but once you know, I got married, I saw the struggles, you know, of my in laws and providing care to my sister in law, because of the inadequate supports and services. There's lack of knowledge and awareness about human rights and disability related laws and policies in India. And I have also experienced, you know, how mind loss experienced affiliates stigma, and discrimination because of caring for her. And I became more aware of the challenges and experiences faced by individuals with intellectual disabilities and families firsthand. And then my husband and I, we moved over here. And we have a daughter, who is also working in, you know, the same world, the disability world, but I did my master's in public health in the US. And then I joined the Department of Disability and human development to work as a project coordinator and research director. And then I got my PhD in disability studies. So you see, I wouldn't have done my PhD in disability studies if I had not met my sister in law and seen how family caregiver gave us experience, you know, struggles because of lack of formal supports, and also sometimes lack of informal supports because of discrimination and stigma. And it has affected us as family pretty deeply. And as a potential caregiver to my sister in law, me, my husband, and even my daughter, you know, we're trying to equip ourselves with, you know, what

knowledge do we need? Or how do we kind of raise awareness about caregiving within our family and advocate for my sister in law's needs? It definitely has given me the opportunity to look at lives of people with intellectual disabilities from close quarters, you know, like, and it helped me develop new perspectives. So my chi life really changed substantially after I got married and my sister in law, both personally as well as my career wise, it's all about, you know, people with intellectual disabilities, about caregiving for people with intellectual disabilities. That's my world now.

C Cory Hartman 09:50

One of the biggest challenges I've had is just really working with my wife and accepting the balance of online versus sip. Live, where she needs to go to all of her doctor's appointments with her, she's involved with every aspect of our life my wife is involved in, and how that, that times, overtake our personal time, our family time, the phone calls that could last 20 minutes up to two hours, because he's hysterical crying about something. So it's really affected my life and be more accepting of schedule changes, or say, okay, you know what, you go do this, you go handle them. And I'll do this without data, or I'm gonna go do this by myself while you enjoy this. So that's been a big, big change in my life. So

C Chris Berstler

what important things about the Civil Law experience? Do you want siblings and other family members to understand? Even? That's

S Sumithra Murthy 10:54

a great question. And I can really tell from my experience that, you know, first of all, every family and every individual is unique, you know, and then every family has different dynamics, it depends upon many factors, such as your socio economic status, you know, whether the person with disability is a male or a female, the country that they live in the kind of social status that they have. And so, you know, like, it all depends on those different family dynamics. But one thing that I would say, which I think could be, you know, common to all families is that we need to approach the relationship with openness, respect, and a willingness to really put in the effort to try and improve the experiences between the family members and also improve the quality of life. And I think I agree with Corey, when he says that, you know, like, he has to kind of understand, if the schedules need to change or you know, like, you have to be pretty open to kind of agreeing to that, and a willingness to put that effort to be more understanding, you know, while sibling loss may have different perspectives, and experiences about caregiving, for a person with intellectual disability than the siblings, like my husband, obviously, we both think differently because of the experiences that we have. But I think it is really important to listen to each other's viewpoints and experiences, to really have a better understanding of the situation and dynamics. One thing that is really important is that I would like to kind of freely communicate here is that it's not only a person with disability, but the caregivers needs also need to be considered the overall Family Well Being, whether it's your in laws, your husband, or you yourself. And therefore each and every member of the family and the extended family as well need to be mindful of each other's needs, and make sure that everyone's needs are taken care of. Because caregiving itself is very stressful sometimes, and

it takes a lot out of you. So we have to make sure that our needs are taken care of, also. And finally, I think, I would like to say that sibling loss, they play an important role in supporting and caring for a person with intellectual disability. So I think we as seventh loss, our opinions and perspectives also need to be considered in decision making processes, I think we can also kind of provide a very valuable input into ways you know, we we are the people who are insiders, outsiders, you know, we have both perspectives. We are an insider, because we are part of the family. And we see what the struggles that the families go through, but as an outsider, because we never had experiences with disability firsthand before we got married. So we have that outsider perspective, too. So I think it's, it's sometimes very important to take the opinions of sibling loss also, because we can come with different perspectives. It might help sometimes it or it may not, but I think just being open to those channels of communication, it's really important. I think these are my two cents.

C

Cory Hartman 14:19

I agree with that. Definitely. And also, if I'm my experiences, this is new to us. So good. Yeah, to give us a little leeway to learn about the changes in the balance on everything. So we might move at a little slower pace, to try to learn about everybody learn about what's right, what's wrong. And don't get upset with us when we ask questions and then even forget that and make a mistake, you know, like I know my sister in law is a 21st She wants me to slow down and you know, so at times I will slow down to meet her needs. And that at times all you had that she'll say but you eat too fast. So it's making sure that they understand that, well, I'm used to eating fast systems the way I do things, and then she'll say, explain why that's not good. And then I always do things fast. So it's really I think, that whole understanding that, like, Sedar, I am new. I'm new to this every day is different. He or she doesn't live with us. We see her every once in a while. So it's still, after all these years, it's still new. Because little little things that she does, little things change little things that I've changed, personally, myself are constantly evolving and growing our relationship together, I think.

S

Sumithra Murthy 15:39

Yeah, I think I completely agree with your career. One thing that I would also like to add here is, you're like my sister in law, she, you know, she considers me as a confidant, sometimes rather than her brother, she'll kind of contract some things to me instead of him because she feels that I would understand. So I think, I think this is also an opportunity to build that one on one relationship with your sister in law. And I think it's, it's very rewarding as seven laws, I think we shouldn't be always worried about how it should be. It can be very rewarding sometimes to and we have to work towards that.

C

Cory Hartman 16:17

Definitely rewarding. I completely agree with you about that. I had the opportunity to spend a full day with my sibling while without anybody else. And we actually had a great time together, we went did something, we painted pottery, we went for food, and it was just a really great chance for me to understand what's going through her mind and really just break that, in law,

stigmatism that goes on? And it's like, this isn't she's my sister in law, but she's also like, my sister, you know, it's let's take away some of these words. Just say she's a family member. And that's what it is, no matter what disability right you like that it's a family member?

C Chris Berstler

Do you have any resources to share with any seven laws that may be listening right now?

S Sumithra Murthy 17:03

I think one resource is definitely sibling Leadership Network. I think I think even listening to this podcast and the work that you do, I think it will offer information and peer support as well. And other organizations that I could think of that could provide support to similars include maybe the arc, there's the national Caregiver Alliance. But I think one most important thing for any civilize to join a lot of family support groups. And, you know, maybe they could go to internet to look for websites for, you know, support and advocacy organizations. That's something that they could do. Luckily, my sister in law lives in Hyderabad, India, which is actually the place where the National Institute for the empowerment of people with intellectual disabilities is housed. And that's a National Institute for people with intellectual disabilities. And they, again, they do have a lot of support groups and a lot of information that they could provide. So anyone in India would kind of, you know, like, guide them to reach out to this institute, which is also called the NIEPID for short. But in India, also, there have been some emerging peer support groups. And I know one called the Ashadeep one called the Nayi Desha. And, and also, there is a whole confederation of family caregivers, which is called the Parivar, which actually means family in Hindi. And they provide a lot of support. And I'm hoping they provide to sibling loss as well, which I'm not sure, but there are these resources. But I think the main point that I want to say is it's better that sibling loss look for peer support groups and family support groups. That's where you know, like you not only get information support, but you yourself get lots of emotional support,

C Cory Hartman 19:02

as well. That our Facebook, there is a seven law Facebook group, which is a closed group for seven laws that allow us to actively talk about what we're dealing with ask input and suggestions, feedback, there's fortunately it's not that active. But there are over 100 members right now, and looking to keep that growing, again, more activity as we keep growing. But it seems to be a great resource, where people you know, say this is what I'm dealing with, what employers suggestions to you guys, or even just personally, hey, here's a picture of me and my siblings, you know, have a great day today. So it covers all that and it's something that is well could we reach worldwide and provide that one on one support as well. Impact magazine, you know, is a great resource as well. My wife wrote an article for when we were getting married about how our family is now changing to be a part of this and all of that. So definitely a great resource that we say,

C Chris Berstler

did the pandemic impact your civil experience? Yeah

and the pandemic impact your civil experience. Thank,

S

Sumithra Murthy 20:10

I think I briefly mentioned this before about how that as part of the challenge question, but yes, it did. You know, my sister in law, as I told you, he lives with my mother in law in India. And she used to go to this institute every day for the day program. And once the COVID, the pandemic hit, they stopped the in person day programs and started with the online programs, it was very difficult for them to execute. And also, my sister in law would kind of lose her attention, you know, and my sister in law herself had her own comorbidities, she was diagnosed with bipolar disorder, so she would have some of those flare ups, or she would end up because of the medication for the bipolar disorder, she used to have tremors so online, because they couldn't do many of the other things, they would ask her to kind of saw or stage something or do something which you wouldn't be able to do because of her tremors. And then they would ask questions like, What's your mother's name? What's your father's name? What's your sister, what's your brother's name? What's your sister in law's name, just to keep their mind active. And at some point, she got so bored of that, and then they will try to make her do like yoga or something, and she wasn't interested. So that, you know, like, it really caused a major decline in her, you know, like, day program, you know, skills and being busy during the day, and she's just at home. Now, I think that has been a major impact. Secondly, you know, we have been extremely careful with COVID. There still are, so they are not able to visit family friends. And if they even if they have to, they have to mask themselves and go. And my sister in law is not very comfortable with masking, she has a hard time with the masks, they're definitely missing out on social opportunities. They did a lot. Now they do go to some of these places and events, but they still wear masks. And after both of them got COVID, you know, they were really worried that it will impact their long term health. So definitely, these have been the impacts. But I think one of the major impacts was on my mother in law, because you know, she could not get respite, like when my sister would go to the day program, that was the time that my mother in law had for herself. But she doesn't have that now. So which is not good for long term, well being of a person when they don't get that respect. So these have been some of the major impacts,

C

Cory Hartman 22:55

really COVID the pandemic didn't really impact her that much, you know, our relationship because she was a homebody, she was stay with her mother. And that's what they would do. You know, who was more video calling that was happening, my wife would order over, make sure they had everything that they needed. So instead of taking care of two houses, we were taking care of three assets. You talked about going online and everything being virtual, you know how hard it was hard to accept a therapy appointment, being in virtual world because it was so new to them. And not understanding how this all works. And just even getting our mind to these points, because it's not like, you click a link and you're right there, you have to log in. And so I from that aspect, it was probably the most hardest part. But other than that it unfortunately, didn't impact us that much the way our interaction was with that.

C

Chris Berstler

Many sibs decide at a young age to avoid finding a partner so they can focus on taking care of their siblings with disabilities. When they get older, as a sibling how what advice might you...

their siblings with disabilities. When they get older. As a sibling law, what advice might you have to share with those sibs?

S

Sumithra Murthy 24:05

I think that you know, although caregiving responsibilities towards their siblings, especially with intellectual disabilities, can be pretty challenging. But it is important for siblings to pay equal importance to their own needs and well being. I think, you can be an effective caregiver only if your own needs are met. And when you have a fulfilling life, right. It's important for siblings to recognize that, you know, caregiving doesn't have to take up all your time, they can still have their social and personal relationships, they can still pursue their own goals. Siblings can ensure reach out for resources and support such as maybe respite care or personal assistance services, or day programs, like I said earlier, and also kind of built a strong informal support system. I think this is really important like the way Corey said they have this Facebook group. I think even siblings should have this online peer support and gain membership to some of these caregiver associations. I think it's really important again, and I want to reiterate that to be a good caregiver, you need to have your own needs met. And you yourself need to lead a fulfilling life. And so I think, for any siblings who are apprehensive about that, the only thing is that they should live their own life, but provide effective caregiving. And for that to do for both to happen, your needs need to be prioritized, is what I strongly believe in.

C

Cory Hartman 25:39

Yeah, definitely agree with that. And also, the biggest things I found very important, or very early on, was talking to your partner or talking and being honest with whoever it potentially may be about your life and how it impacts you. And that if things become very serious, what how the role is going to transition for you and your significant other. And I think that that's probably one of the most helpful thing was with my wife, you know, our first day was over eight hours. And we talked about my children, she talked about her sisters, she said, if this goes anywhere, just so you know, this is part of who I am. And this is, so that honesty piece is such a big, big part of it really early on. So you have the understanding, and you're gonna hit roadblocks, where people are like, No, I don't want to deal with this. And then you're gonna find that person, but don't block yourself out from living a life either. Definitely, the biggest thing probably,

S

Sumithra Murthy 26:41

I think, can I add something to this, and this is related to India, like, you know, I understand Korea, like, you know, you have this opportunity to talk with your partner about and being honest. But then India, sometimes there is this arranged marriage system, right, where you may not get that opportunities, and a lot of families, they get really apprehensive about, you know, finding a match for their, for themselves, because they have a sibling with the intellectual disability, there's a lot of stigma attached to having a sibling with intellectual disability, especially on Developmental Disabilities, or any disability, as well. And that is where I think the attitudes in the society needs to change, I think there'll be less apprehensiveness to get married, if they know that, you know, like, it's not so stigmatized, to be a sibling, who has the person with disability as a sibling. And therefore, I think that also is important things are changing in India as well now. And I do understand that, you know, right now, there is more

communication between the prospective bride and groom even before their wedding. They do need to communicate with each other. But I think what one needs to get assured of is that there are resources out there that we can kind of Garner to kind of support and I agree with you, Cory, I think it's very important for the partners also to understand that, you know, life is not going to be easy, you will hit roadblocks, there are a lot of things that you may not understand. But I think one, a strong support system in the family and outside resources will be very helpful.

C Chris Berstler

Do you have any advice for any potential Sivan laws? who are considering partnering up with ACIP?

S Sumithra Murthy 28:40

Yeah, I think as I said earlier, there has to be open and honest communication between, you know, this person that they might eventually, you know, marry or you know, live it. But along with that, I think the potential sibling loss or the prospect of sibling loss have to kind of look for resources beforehand, I think they need to understand they need to read more about how is it to live with a person with a disability or an intellectual disability? What kind of resources are there? What could be your role? And what could be family members role? What could be the family dynamics, understanding what family quality of life is and how it's impacted because of a person with disability? I think if a person gets into the relationship with this knowledge beforehand, I think that will kind of help and I think one thing that I can tell you based on my experiences, having that relationship with your in laws, you know, like mother in law and father in law, to understand how they raise their child with intellectual disability, and what are their perspectives and what are their expectations about you? I think that's really, that's really important. I remember when I got married, my mother in law told me, please take care of her well, because there is no one else. Like, if you don't take care of her, well, our family will crumble. And I understood where she's coming from, because my husband being the only other sibling, she knew that if I wasn't nice to my seventh law, the family will be unhappy. So she and I understood that from her perspective, so it's very important to have that kind of communication and understanding of your parents in law's perspectives about what they're expecting from you, about their child with intellectual disability, and how you could add value value to the family dynamics.

C Cory Hartman 30:47

I agree that your education is the biggest part of everything. From personal experience, I think a big part of it was talking with my own family, about what I was going into and all the support I would need from them as well as other people. And it came the question of well, Is there potential, you guys, when we will get married? Are you going to have children because of this being, you know, something that could be hereditary and things of that nature. Also, don't be afraid to say, You know what this is, this sounds like a lot for me. Because you don't want to get into something where if it doesn't work out, you're not just impacting one person, you're potentially impacting a family, that that could have such a negative and long term lasting impact on because if they really liked you, and you leave that, you know, that impact might not

be handled? Well, you know, it could be used in so many different ways where it's our it's my fault, this happier. Yeah. So I did be honest with both parties, on what you think you can manage, I can't manage, what would you say

C

Chris Berstler

is the best part of being a seventh law,

S

Sumithra Murthy 31:59

you know, with my seventh law, with my sister in law, I do. Like, as I told you, she loves jewelry. She loves, you know, dressing up. So I really enjoy taking her out to shopping and you know, buying things for her. She enjoys movies. And so I enjoy, so I really enjoy doing what she likes. But you know, for me, again, the difficult part is that we live in two different continents. Which is unfortunate. But that's at some point. I think she will come and live with us in some form and some capacity, because I don't know how, based on the visa issues and all that I don't know what is going to happen, but we know that we are going to be potentially future caregivers for her. And I'm prepared for that. And I know that it will not be difficult as it seems, because I'm going to explore for resources and gaining knowledge. So So I think the best part coming back to the question on best part, I think, I'm sure whenever we are together, whenever I visit her whenever she's here, we do have fun, because I buy things that she likes. So she's pretty happy. And then we talk about a lot of things and do the things that she likes, I think so that is rewarding, you know, like seeing your sister in law. You know, being happy with what you're doing for her is very rewarding again. So I think that's the best part.

C

Cory Hartman 33:35

So for me, I would have to say that it was more of an eye opening experience for me to learn about myself, and make changes in myself on the way I handle different things and be more open and honest on my abilities, knowing that I cannot spend a full weekend in a two bedroom apartment with them. But I could spend a day or two. But I could also go on a cruise with them just as long as we have different rooms and understand that they might not appear at certain things. So really teaching me the value. understanding and acceptance was a big part of it in a different way than normally established. And also just seeing the interactions between all three of my girls really also add so much value to myself and that just because there's that title, doesn't mean that they can't be all together and enjoy in life, you know.

S

Sumithra Murthy 34:43

Yeah, and I would like to add to that also, like, you know, when I actually completed my PhD and I definitely acknowledge my sister in law for you know, like, I wouldn't even have thought of doing PhD in disability studies if it was not for my sister in law. On my mother in law as well, because as a family, I saw what they were going through. So I give huge credit to my husband's family for kind of initiating me into the world of disability studies and understand their perspectives closely.

C Chris Berstler

Do you have any other words of advice or any final pieces of information that you would like to share with everyone, before we wrap things up?

S Sumithra Murthy 35:24

You know, I would like to just reiterate what I said. And I could kind of, say it concisely that you know, your role. If you're a sibling, your role in family is really important. And you can definitely contribute to family decision making process meaningfully. And, you know, please do not hesitate to reach out for help, either from family or friends or from any other formal resources, like Cory mentioned right now, you know, be a self advocate, advocate for your needs and your preferences, but also advocate for yourself in law, you know, so that we can provide the best possible care. It's a, it's definitely a very rewarding process. And, you know, understanding the lives of people with disabilities and their families gives her altogether different perspective, and it will definitely enrich your lives.

C Cory Hartman 36:17

I think that like, again, the big thing I would say is communication. Communication is key. Don't be afraid to ask questions, say how you're feeling via your own support system as well. You also have to really stressed and I wish I did more, myself is trying to have that one on one time, with you said, just because that creates a whole new level of a bond and relationship, and acceptance and all it really helps. I think everybody grow in the same fashion. So that would be what I want people to take away.

C Chris Berstler

Thank you both so much. This has been great, at least for me to hear, as I said, so anyone listening any resources that were mentioned during the podcast can be found in the description below. Thank you again so much for joining us today. This has been an absolute pleasure.

S Sumithra Murthy 37:09

Thank you for having us. Thank you. And we very much appreciate the time that we spent and was nice to talk about, you know, being a seventh law. There are very few occasions that we get to talk about our experiences, so thank you for the opportunity.

C Chris Berstler

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