
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 welcome to another episode of the sibling Leadership Network Podcast. Today we'll be talking about SLM chapters what they are and why and how to get involved. I'm joined today by founder of one of our first chapters, Wisconsin's Harriet Redman and founder of our newest chapter, Oregon sibs, Nikki Donley. Thank you both so much for joining us today.

H Harriet Redman 00:46

Thanks, Chris. It's a pleasure to be here.

N Nikki Donnelly 00:48

Thank you, Chris.

C Chris Berstler

Please tell us about yourself and your siblings.

N Nikki Donnelly 00:53

So I'm Nikki Don Lee and recently moved to Oregon via I was in Illinois for a couple years working on my doctorate degree. And then but before that, I was from California, and very involved, very still involved in the California Chapter of the sibling Leadership Network. And I

moved to Oregon and realize there was not a chapter here and wanted to connect sibs in this area, I have a brother who is 10 years younger than me with autism. And he's the absolute love of my life and why I'm my profession is in special education. And I'm currently an autism consultant here in Southern Oregon. Yeah, he's influenced my work so much, and taught me everything I know, I say, and I do have an older sister, three years older than me. And she, and my parents and my brother currently live in Alabama, where when my when I lived in California, my brother lived with me for 1011 years before he moved to Alabama, when I moved to Illinois to pursue my degree. So glad to be here.

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Harriet Redman 02:13

Oh, my story is a little different in that I'm not a sibling, I'm a parent actually. And, and yet, my heart is where siblings lead us in understanding how to treat people with disabilities and how to manage all the many roles that siblings have to manage. So I have two grown children. Christiana, who's 33, and her younger brother, Philip, who's 30. And my interests began, when Philip was born, he was born with a multitude of disabilities, and no specific diagnosis. So rare chromosomal abnormality, which kind of was one of the reasons that I was able to pursue looking into the research on siblings in that there was just really nothing to look into with my son. But more importantly, I immediately understood the implications of parenting, a child with a disability and their sibling. And so part of that was my, my natural, intuitive motherhood sense. But also, my background and education was in family, education, and, of course, studying family system theory and all that kind of thing. So I knew that this would have implications for his sister, her whole life, because it's a system. And I felt very unprepared to know how to support her as well as how to parent children who had very different kinds of needs. And this was back in 1992. So ancient ancient history here. But at that time, there just wasn't much information at all a very little research. But I sought out what I could, and I found SIP shop, thanks to Don Meyers book, which was in a bookstore that and I sat down in the bookstore and read it from cover to cover. And it really answered many of my questions, but also made me even hungrier to help others who like me as a parent, but also siblings find each other as that that is so important in the strength and resilience of siblings is that they they find each other and they They support each other.

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Chris Berstler

Please tell us about your respective SLN chapters and how you became involved with the SLN.

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Harriet Redman 05:08

As I was looking for more information, and was frustrated and amazed that there was really nothing out there, but if you think about it, the the laws for to support people with disabilities and integrate them in the community were pretty fresh. And, and there wasn't a lot of data on siblings growing up with brothers and sisters with disabilities. But having said that, I did find not only Don Meyers book, but I found some school psychologists who were also interested in pursuing what could be done to help siblings. Long story short, we decided that we would offer SIP shops, then we determined that you can't do that endlessly without some sort of support. So we started a nonprofit and we called the Fox Valley sibling support network. And those

listeners in Wisconsin might know where the Fox Valley is. It's the area between Green Bay and Oshkosh, Wisconsin, so it's Northeast Wisconsin along the Fox River. And so that's where we started

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Nikki Donnelly 06:26

my original connection with the sibling Leadership Network. I think I was on meetup.com probably looking for social connection opportunities for my brother or something when he was living with me many years ago. And I, I just accidentally came across California, saline and, and I'm from the Central Valley area of California. And the group was meeting in San Francisco. So it was like a two and a half, three hour drive. And I drove there to meet up just because I was like, What is this about? I want to explore myself as a sibling. Right? And what is it? What does that mean? And why did I never even thought of myself as this unique community, you know, it just never even occurred to me. And I connected with them. And then I ended up because California is so large, there's kind of like a Northern California group and a Southern California group. But the Fresno area is like right in the middle, and you're like three hours to either group, right? So I started a, like a Central Valley Chapter, they're not chapter but you know, area there. And we expanded our, our people connected with the California group, right. And, really, we've, that, that grew just immensely. And so I continued with the group. And then when I moved to Oregon, just really wanted to create that sense of community here in Oregon. And it's really been amazing, because I'm still there's, there's a couple projects ongoing with California, then I'm still on, I'm still on the board there. But we're partnering now. So instead of it just being like a California project, now, we're bringing in our people that are involved in Oregon as well. And, you know, we're all volunteer, it is 100%, volunteer, all of California, all of Oregon, we're not paid for what we do. So the more people that we can have involved, the less effort I'm you know, work in time that we have to do, you know, because we have great big ideas that we want to have things that we want to accomplish. But, you know, we work and we have families and, you know, we're still many of us are caring for our siblings or in some, some way supporting our siblings and still are helping them navigate systems and so forth. You know, and yeah, so, so time tends to be a big constraint. A lot of the a lot of it so I've really, really enjoyed just setting up this collaborative partnership with with California and Oregon.

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Harriet Redman 09:37

Chris, your your audience can't see us but I'm nodding my head with everything that Nikki is saying. Collaboration, end and connecting, partnering, taking the small steps to get to the big steps. It takes all of that and and in that process. It's it's sometimes easy to give up, or just say, Well, you know how, how critical is this? Maybe it's not so important. I better take my time and do something else. It is important. And it does make a difference. And it does take one step at a time, with a lot of people focused on the prize, and that is connecting siblings reassuring the resiliency of siblings. And that's just critical not only for the sake of siblings, but for the where their eye is in their eyes on the quality of life for their brothers and sisters

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Chris Berstler

Wisconsibs existed 10 years before getting involved with the SLN in Oregon sibs is the newest SLN chapter, why did you decide to become SLN chapters and what can a chapter or an individual sib do once they are part of the SLN that they couldn't do before?

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Harriet Redman 11:01

When we started, and I mentioned that we were called the Fox Valley sibling support network, we didn't really have a vision of becoming statewide or nationwide, we were we were focused on the needs of our local community. We weren't looking outside that. But as we moved along, as we began to collaborate with more and more and can see the value in a broader relationship with organizations and siblings, from, you know, beyond our small community. It, it just seemed like a really good idea not only to connect our siblings with one another physically in person, but helped connect siblings together wherever they're from. So when, when we were approached by some of the organizers of other states to come together and think about a national effort, a national movement, we weren't even talking necessarily about an organization, we weren't sure what we were talking about, but really perpetuating a movement of sibling awareness. I thought this is fantastic, because sibling awareness is is going to be critical, not only for each individual's life, but for policies for research for global connection. So yes, we were definitely interested in getting something bigger started. And as it turns out, the way that sibling Leadership Network chose to grow was by state chapters. So for us, that meant we needed to think a bit broader than our small community, we needed to think, statewide. And so we also changed our name from Fox Valley sibling support network to Wisconsin's so that we, we presented ourselves as a Wisconsin chapter.

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Nikki Donnelly 13:22

So why become involved with the SLN and I think once once I got involved with California, I realized, like the power of us siblings coming together and for for myself, just, wow, I learned so much about myself. Like, there's this whole community out there that probably doesn't even realize they need community. Right. I never thought about it before, you know, so. So, yeah, I think, really, I I'm just very passionate about the mission of the SLN and advancing that. However it need be. And, you know, the power of us all coming together when I look at because I'm currently still on the board for the National SLN and hearing the updates and, you know, the policy committee advocating for every state to include siblings in the Family Medical Leave Act, you know, and I'm happy to say Oregon just passed a Family Medical Leave Act for the first time and or the Oregon Medical Leave Act. I'm not sure what it's called. But the first thing I did was when I saw it was proposed was pulled it up and yes, siblings are included. So kudos to Oregon for including siblings. Not every state does so You know that that's an example of having that advocates that collectively come together? You know, and and you're, you're pulling from the the the knowledge and the skills of people from now across the United States, rather than just from your community or your state, you know, you can, it's, again, that power of collaboration, right. That's the power coming together. And and I'm also co chair on the research committee right now. And, and, you know, we're bringing in researchers from across the United States come together and, and collaborate on what are the needs, what are the studies, or even just compiling all of the research together in this nice document that, that we have, so that other people that are doing research can tap into what what we have, you know, and use us and for recruiting and so forth. So, yeah, that now the national reach even being in a small southern Oregon, I know that I'm connected nationwide.

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Harriet Redman 16:18

And I think that's so critical. And one of the reasons that I was hungry for a national presence. My experience in looking for research right away when, when my son was diagnosed, I mean, there wasn't much and part of it was it wasn't pulled together. And, and yet, as I was fostering this new nonprofit, I, I didn't have time to do all that research and all that searching for research. So I was hungry for that national presence, that national connection to, to do that for us, and an end to inform us as a part of a larger network. So it was the research and as you said, the advocacy that even as a state organization, we don't have the capacity to do that. All by ourselves, we really need the the the force of a nation wide organization, like the SLN.

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Chris Berstler

Why is it important to have a place for sibs to get together?

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Nikki Donnelly 17:34

Oh, my gosh, I'm going to jump in on this one. Because this is I'm so so passionate about this. For me, I can say myself, personally, I kind of look at this twofold because, you know, being in the profession. And being a sibling, is is has been a very wholesome experience for me, I guess. And I, as a sibling, I have learned way more about myself, then, I, I would have never known this about myself, if I've been on this journey of learning and understand myself and why I do some things that I do. And many of it is related to being a CIP. You know, I, I point out that probably the biggest thing that I've learned about myself in learning about what it means to be a sibling and in listening to, you know, Don Myers, my present his research and so forth at conferences, as I was just getting involved, is I never I prided myself on being self sufficient. Right? And I never, like, I never looked at it from the perspective of like, I don't like to ask for help. Right? Because, not that it was ever intentionally said to me, but I think as a young child, now remind you, I'm 10 years older than my brother. So I, I wasn't young, you know, I, when my brother was, was starting to go through assessments and diagnosis when he was two or three, I was 1213. So I was very aware. But I also, I think, was very aware that it was very, very taxing a time for my parents, right? And in what what all they had, like him being kicked out of preschools, and, you know, just trying to manage their work life balance that I just kind of got this like, Oh, if I need something, it's a burden for somebody else. So now, you know, I've learned to navigate that through my life. And so the power are for me personally and just understanding myself has been one of the the, the absolute greatest gifts that sibling Leadership Network and has has given to me. And I'm extremely thankful for and I in turn when it gives that back to other siblings,

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Harriet Redman 20:21

everyone needs to feel they belong. And that's what I observe with with siblings who find us. And we, we have programs starting at age three all the way through adulthood. And when they find other siblings, and they find, they may not even have thought of themselves as a sibling, or as we say, or Wisconsin, or a said, until they hear other people start to describe their experiences. And then it dawns on them, oh, I'm a sieve. And look at all these people around me. They're okay. This is going to be okay. And that feeling of belonging and relating, and the you said power, the reassurance. The empowerment that offers is immeasurable. And, and it might be just a little flicker, it might be just a little moment, that makes a huge, huge

difference. Recently, we have a new board member, and she was seeking out information for her, her nephew who is the brother of a young boy with autism. And in her journey to find us for him, she realized that she too, was a sibling. And just, I wish you were here to tell you how that made her feel pretty empowered, pretty excited. And, and like, I found something I didn't know I was looking for. And it feels really good. I think another reason that it's important to connect with other siblings is that you, you have someone to reflect on someone to feed back the way you see yourself, though, the way as you were saying before Nikki, to discover yourself, discover your strengths, discover what role you're playing, even to define those roles is absolutely important. And, and I, I do think that as a parent, I am able to help siblings reflect that as well, because it's just another perspective. And I'm also an advocate for siblings that their voice within a family needs to be heard that parents need to listen to those siblings regardless of their age. And, and understand them for their roles and their perspectives. for lots of reasons, including that they have the longest relationship with their other child with a disability. That's critical.

C Chris Berstler

In your opinion, what is the best thing about your chapter and why should and how can siblings in your area get involved?

N Nikki Donnelly 23:27

I think right now with Oregon, we're, we're we are just starting to bloom right. And so there's so we're so open for ideas and opportunities. And, you know, come Come be with us and bring your idea and we're gonna help help nourish it right to bring it into fruition. And so, yeah, and as far as connecting with us, right now we're on meetup.com and it's Oregon sibling Leadership Network and we have a Facebook page. Oregon sibs. All one word.

H Harriet Redman 24:13

Since we've been operating for more than 25 years, we have, to some degree, reached our vision. And our vision was to have programming for siblings of all ages. So one of the exciting things about us is that we have programs available from age three all the way through adulthood. For three year olds, it's a program called SIP sack and it's a tangible bag of materials that really emphasize the relationship with their sibling with disability, how much love there is in their family for them as well as their sibling with a disability using the word disability and And helping parents through the activity book for children hear and be open to communication with their brother or with their child with you as a brother or sister with a disability. So all the way from age three through childhood through teenage through adulthood, we emphasize that, for adults, we have programs for helping them with future preparation. We call it journey forward. And, and now the the, the main focus is, we've got these programs, now we need to get them out further and further, throughout Wisconsin and elsewhere to where we always claim that we don't care if you live in Wisconsin, but if you like Wisconsin, or you're a Packer fan, or you drink beer, you can be a Wisconsin, that's good with us. So we really are pretty open with that. But in the process, we also want to reach each and every sibling we can, here in Wisconsin and beyond

C Chris Berstler
what current issues are unique to siblings in your area?

H Harriet Redman 26:15
Well, I'll start and it's probably not news that services, especially housing, caregiving, all of those services are so difficult to get for their brother or sister with a disability. So and as those systems and services are a scant, those responsibilities then come to the family. And their parents are getting older, they're getting older, they're busy. Those are all big challenges for our adult siblings. And we recently did a future planning program is really Forward program as a live workshop. And the siblings attending that were the youngest group of siblings ever, ever to go through the program. So it's not just older siblings that are realizing the magnitude of it, the scarcity of services and services, but the aging population is really becoming much more evident. And it's here, it's a caregiving crisis. It's a housing crisis. And that's really concerning, not only adult siblings, but even teenagers and, and children, young children understand the, the, the weight of responsibility, that that they either perceive, or they know they have,

N Nikki Donnelly 28:03
we're still learning about the needs in our area. In fact, we are partnering with California, we're putting a research team together to kind of learn about just survey siblings in California and Oregon and, and we'll be open to other states if anybody else wants to join in for that. But I can say, hey, you know, I'm reflecting on our little Oregon startup board. We all have siblings that are in different states. And us we're Oregon is very rural, as well, right. Unless you're up in the very North Portland area, you know, we have little pockets of larger towns, but for the most part where it's very, very rural. So yeah, and just learning and understanding how to connect that way. Thank goodness for virtual sessions. Right. But then, you know, you hope, you know, there's there's lots and lots of rural places in Oregon that do not have internet access. Even that's a barrier. So

H Harriet Redman 29:07
right, Wisconsin, too. Yeah. When we were 10 years into our, our journey, our Wisconsin's journey. When we were when we felt we were ready to add adult sibling programming. So we did a quite a number of focus groups of adult sibs and professionals who had, who were aware of siblings that that were in the picture. And they were concerned about the quality of care for their brothers and sisters. And while we didn't see in our mission that that we we could change the quality of care that their brothers and sisters were getting. We did give siblings a tool that other chapters could read. replicate. And that is we give siblings an opportunity to nominate quality caregivers, people who are caring for their brothers and sisters, we call it the siblings Choice Award. And we give it in November, which is national family caregiver month, I believe it's called. But it just gives siblings another tool to have a little power to emphasize the importance of quality care for people with disabilities, because they do care about their brothers sister, even if they don't want to be, you know, they don't want their sister illumine with them. And their sister doesn't want that either, or whatever the case is. They do care. And

this is one tool they have control on they can acknowledge and recognize and honor people who are providing that care. And it's small, and we don't there's no cash prize or anything. It's small, but it is it says to the world. Similarly, as you're watching, they care about this issue.

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Chris Berstler

Does your chapter have any upcoming events or initiatives that you're looking forward to?

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Harriet Redman 31:15

Well, we have a lot of stuff coming up because of our lifespan of programming. So September always means that we're kicking off CIP shops, and we have those monthly for ages six to 12. Don't one of them is with a conference. And we love to do those where autism conference might be taking place some part of the state or we have a circles of life, which is any diagnosis, we will provide the sub shop at those conferences. So we have one of those coming up in September as well. We are we have started a adult book club called Wisconsin's read. And so I always look forward to those they they even though I'm not a sibling, they, they graciously let me part of that. And it does not matter what the book is, and and we don't pick books that are necessarily about siblings. But it does not matter what the book subject is. The conversation always ends up being a sibling conversation. And it's wonderful, it is absolutely wonderful. And anybody can join that. We will be meeting September 20. I'm not sure we have a book for this month. But those are, those are fantastic too. And we're also working on putting our journey forward program online, that will be a few months down the road. But I'm working on that. And I'm looking forward to that.

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Nikki Donnelly 32:48

We have upcoming Oregon intro to sibs, it's virtual. So we invite anybody from everywhere, there's only one slide that kind of talks about statistics in Oregon. So the rest of it is is pertinent to anybody. And that information actually just went out in the SLN September newsletter, so but it is Monday, September 25, at 6pm. Pacific Time. And other than that we are we have a mental health professional that we're partnering with and doing it's like a six week meeting one time a week kind of workshop. And so we're, we're before we put it out to public, we're piloting it with board members so that we can kind of fine tune it and and it's for siblings to to really dive into those that want to go deeper into to this mental health aspect of it. So that'll be coming in the future.

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Chris Berstler

what advice or resources would you recommend to any listeners out there who live in a state without an SLN chapter?

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Nikki Donnelly 34:08

reach out to the SLN and start one yourself if if you don't have the bandwidth to do that, because you know, it's a task I'm still working on. You know, this is all currently kind of self

because you know, it's a task I'm still working on. You know, this is all currently kind of self funded. So there's money that takes into like setting up a Google Suite and you know, having a meetup site and so forth. So if that's not in your bandwidth, then connect with another state. You know, and then as as you grow, like maybe people in your state that are connected with another state, then then it kind of you can you can spread the love across more people and you don't have to do it all on your own. I was very, very fortunate when I moved to Oregon and realize there was not a chapter I reached out to the SLN. And I said, Hey, and they said, Well, we actually had these couple people that have shown interest in the past. But again, probably didn't individually or whatever, you know, hadn't been with the growing of a chapter. And so when I reached out to them, they're like, oh, we have these couple people, connect with them. And then so it was, it was nice that there may be people already interested in your state. So if you reach out to the SLN, they can, there they have their little tickler list. And when I reached out, they there, I was able to connect already. So

H Harriet Redman 35:42

yeah, that's great advice. Nikki, we've done that many times. Early on, and even more recent, it's, it's fun to find out what's going on in other states, but reaching out to other SLN chapters, reaching out to anyone who may be interested in supporting your cause. And that that can mean non sibs, that can mean parents that can mean professionals. Just tell your story, just if you say it often enough, it's always good to say that out loud and sort of therapeutic. But also, you'll find people who are interested in what you want to see happen, have that vision ready to talk about. And, and don't be afraid to reach out to people you didn't expect, that would be interested. And don't give up. That's the other is, there's all kinds of reasons to stop. But don't just keep going and don't give yourself time be patient. It doesn't happen overnight. But when you're feeling discouraged, you know, given SLN chapter person a call or email, Nikki, myself, on the other 27 states that have people who are working on this, I'm sure we'd be happy to give you some encouragement.

N Nikki Donnelly 37:11

I want to also highlight don't forget connecting with schools, you know, because a lot of times, it's special education. systems within schools are required to have family component to it, right. So like we do intro to sibs, for several school districts that do parent training workshops.

H Harriet Redman 37:36

And if a school is not open to you find another school.

N Nikki Donnelly 37:42

My dream would be to have six shops as part of you know, they have after school clubs and so forth, even at elementary school, like my dream would be to have us at elementary, you know, just another after school club. Right?



C Chris Berstler
That would have been nice growing up,

N Nikki Donnelly 37:57
right? Yep, just the power and having people in your community that that can help you navigate through this this sieve life.

H Harriet Redman 38:12
And I like what you said Nikki to it. You don't have to organize a whole bunch of stuff to seek out support. That affirmation that you you can get when you know one other person who may be a sibling, or may not. But siblings talking to other siblings is so so much a gift that if you are an organizer, and you can make that connection happen. It's worth every thing you did to make it happen. All of the planning all the all the thinking, and even if it costs the money, it is definitely worth it worth it. That connection is so, so important.

C Chris Berstler
Awesome. This has been such an excellent discussion. Thank you both so much for taking the time to share with us today. Any resources that Harriet or Nikki have discussed, will be in the description below. Yeah, thank you both again, so much for being with us today. It's been great.

N Nikki Donnelly 39:22
Thank you, Chris, for having us.

H Harriet Redman 39:23
It was fun.

C Chris Berstler
Find resources, tools and information about the sibling experience on sibling leadership.org. The siblings 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.