



**WELCOME
to the
2019 National SLN Conference!**

THE MISSION
of the **Sibling Leadership Network (SLN)**
is to provide siblings of individuals with
disabilities the information, support, and
tools to advocate with their brothers and
sisters and to promote the issues important to
them and their entire families.

www.siblingleadership.org

#2019SLN

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SATURDAY KEYNOTE

Sibs Matter! Why everyone must attend to brothers' and sisters' concerns

Don Meyer



Don Meyer, the award-winning founder of the Sibling Support Project, author, and creator of the Sibshop model has presented on issues facing families of people with special needs all over the world. Don created Sibshops, which provide peer support and information to thousands of young brothers and sisters of children with special health and developmental needs. He is a best-selling author and editor of seven books on families of people with special needs. Don's trainings on the Sibshop model have resulted in the creation of over 450 Sibshops throughout the United States as well as Argentina, Canada, Chile, Iceland, Ireland, Italy, Japan, New Zealand, Trinidad, and Singapore. He has presented more than 300 lively, highly-rated workshops on the concerns of siblings, fathers, and grandparents of children with special needs to professional and family audiences in every state as well as Argentina, Canada, England, Germany, Guatemala, Iceland, Ireland, Israel, Italy, Japan, New Zealand, Taiwan, and Turkey. Don was a founder of the University of Washington's SEFAM (Supporting Extended Family Members) program, which pioneered services for fathers, siblings, and grandparents of children with special needs. Don created SibTeen, Sib20, and SibNet, the Internet's first and largest online groups for young and adult siblings of people with disabilities, reaching over 5000 siblings every day.

SUNDAY KEYNOTE

*Generations: Sibling journeys, lessons,
and triumphs across the years*

**Lynne Calloway, Leah Alexander,
Layci Calloway and Alex Calloway**



Pictured counter clockwise: Layci, Leah, Darrell, Alex, Lynne

Lynne Calloway is Leah’s older sister and “bestie”. She’s an educator and 35 year veteran of the developmental disabilities services field serving in a variety of managerial and family support roles, and former Ohio Adult SIBS board member. Lynne is married to Darrell. Among her very favorite roles is mother to Layci and Alex.

Leah Alexander was born in 1967, before IDEIA, and when parents were still being directed to “put their children away for the good of the family”. She is award-winning advocate, employee, a volunteer, fringe artist, and caring sister.

Alexander “Alex” Calloway is the youngest of the Calloway family. He’s is Sales Representative with a major automotive company, is completing an Associate’s degree in Aviation Science, and recently completed all FAA ground and air requirements to become a commercially rated pilot.

Layci Calloway is eldest of the Calloway children. As Alex’s big sister she was a tough act to follow, but a loving, supportive role model. Layci serves as Global Strategist and Product Manager for an international medical technology group.

AGENDA

Saturday June 22, 2019

8:00 am: Registration and Continental breakfast (Minnesota Ballroom)

9:00 am: Welcome and Introductions (Minnesota Ballroom)

Welcoming Remarks, Colleen Wieck, Ph.D., Minnesota Governor's Council on Developmental Disabilities, Executive Director

Strengthening the Sibling Network Together, Katie Arnold, SLN Executive Director

10:00 am: Keynote Presentation (Minnesota Ballroom)

Sibs Matter! Why everyone must attend to brothers' and sisters' concerns

Don Meyer, Founder of the Sibling Support Project, Author, and Creator of Sibshops

Despite the significant roles they assume, siblings of people with disabilities are often excluded from the functional definition of "family." For the benefit of everyone (especially the family member with the disability!) parents, providers, and policymakers must attend to sibs' concerns. During this keynote Don Meyer, founder of the Sibling Support Project and Sibshops, will discuss why siblings are too important to ignore, the common concerns experienced by brothers and sisters throughout the lifespan, and what everyone can do to give siblings the seat at the table that they richly deserve.

10:50 am: Break

11:00 am - 12:15 pm: Morning Breakout Sessions (Choose one of the four options below)

A. *Siblings: Resources, Emotions, and Caregiving* (Governors I)

Shruti Tekwani, Licensed Mental Health Counselor

Sandra Tucker, President, Sibling Tree

Having a sibling with disabilities can come with its fair share of physical and emotional challenges. This presentation will address how to understand ourselves in this sometimes complicated world along with managing the needs & wants of our siblings and families. We will explore 3 main areas: Self-Care, Guilt, and Loss which will include identifying stressors, developing ways to manage and reduce stress, define respite, discuss access to resources and connect siblings to support networks.

B. *Our Siblings Are Sexual* (Governors II)

Kaley Day, Advocate for Adults, ADVOCACYDENVER

Our siblings are sexual aims to get siblings talking about the "uncomfortable" topic of sexuality and disability. Attendees will gain an understanding of the differences in sexual messaging and education for people with disabilities, gain insight on the implications of values on sexual self-advocacy and learn how to approach the topic with family and providers.

C. *Sibling Relationships Around the World: Experiences of Siblings of Special Olympics Athletes* (Minnesota Ballroom)

Meghan Hussey, Senior Manager of Global Youth Engagement, Special Olympics

Ashlyn Smith, Senior Manager of Research and Evaluation, Special Olympics

Alicia Paul, Sibling Engagement Fellow, Special Olympics

Staff from Special Olympics International will present preliminary findings from a cross-cultural study on sibling relationships for people with and without intellectual disabilities. Special Olympics is an international movement that provides opportunities for over 5 million athletes with intellectual disabilities and their families in over 172 countries. In an attempt to understand sibling relationships across the globe, Special Olympics conducted a study of sibling relationships in the Latin America, Asia-Pacific, and Africa regions. The aim of this qualitative study is to gain a deeper understanding of the experiences of siblings of Special Olympics athletes using focus groups comprised of siblings ages 8-25. More specifically, the goals of this study are to understand the positive and challenging experiences of siblings of Special Olympics athletes as well as their specific support needs. The presentation will demonstrate the nature of youth sibling relationships, explore how those relationships may differ by region, and engage audience members to identify ways in which siblings across the globe can be supported in future efforts. Following the presentation of findings, there will be a Q&A for the audience to share personal experiences and discuss how these findings may help determine best approaches to providing sibling support in different cultural contexts.

D. *Supported Decision-Making and the Role of Siblings* (Governors III)

Tina M Campanella, CEO, Quality Trust for Individuals with Disabilities

Supported Decision-Making (SDM) is quickly becoming a preferred way of supporting adults with all types of disabilities to make decisions and retain control in their lives. Unlike guardianship, SDM provides whatever assistance people may need to make decisions in their lives without placing any limitations on their rights. The assistance needed is most often provided by family and close friends who are selected by the person because of the trusting relationships they have developed. This presentation will outline the essential elements for using SDM with attention to the requirements for the role of supporter – especially if the supporter is a sibling. The presenter will explore the many ways people can get assistance and the most effective strategies for providing help. There will also be opportunities to discuss how SDM strategies can be used even if a guardianship is already in place to empower and respect the person with a disability.

12:20 pm: Conference photo (Minnesota Court) - Join us for a group photo!

12:45 pm: Lunch (Minnesota Ballroom)

1:15 pm: Sibling Panel (Minnesota Ballroom)

Sibling Panelist Facilitator: Don Meyer

Sibling Panelists: Will Bubenik, Chun-yu Chiu, Claire Haas, Katherine Hamann, Alicia Utecht

Listen to a wide range of sibling experiences and perspectives from this intergenerational panel.

2:45 – 4:00 pm: Afternoon Breakout Sessions (Choose one of the four options below)

A. *Disability Policy Updates and Strategies for Legislative Involvement* (Governors I)
Tiffany Banks, Licensed Clinical Social Worker, Board President of Sibling Tree

While getting involved in policymaking can appear overwhelming, this presentation will aim to make the legislative process accessible for allies and self-advocates of all kinds. Tiffany will provide an easy to understand update of current policy issues from D.C.; while articulating how to get involved from a local, state, and national level

B. *Research and Implications for Siblings of Individuals with Disabilities* (Governors II)
Meghan Burke, Ph.D., SLN Chair of Research Committee, Associate Professor of Special Education, University of Illinois at Urbana-Champaign
Chun-yu Chiu, Ph.D., SLN Co-Chair of Research Committee, Assistant Professor in Special Education, National Taiwan Normal University
Nathan Grant, President and Founder of Siblings with a Mission, SLN Board of Directors
Chung eun Lee, PhD, Postdoctoral Research Fellow, Vanderbilt University Medical Center

In this session, we describe the findings of three studies about siblings of individuals with disabilities. The first study examines the experiences and support needs of siblings in the context of a rare disease and highlights strategies to promote effective interactions between siblings and health care professionals. From this study, participants can learn about resources and initiatives developed to help siblings navigate their brother or sister's medical care. The second study will examine the experiences of pre-adult siblings of individuals with intellectual disability and autism in Taiwan, with two specific aims: to (a) understand their experiences and (b) identify adequate support strategies in collaboration with stakeholders (i.e., adult siblings, parents, professionals). From this study, participants will develop an understanding of the cross-cultural sibling experience. The third study will examine sibling participation in individualized service plan meetings for their brothers and sisters with disabilities. From this study, the participants will learn about how to navigate the service delivery system with their brothers and sisters with disabilities.

C. *Woody's Order!* (Minnesota Ballroom)
Ann Talman, Actress

Broadway actress Ann Talman will share the 16 minute documentary based on her solo play. The play *Woody's Order!* details Ann's struggles to understand her brother's disorder, build a career, and sustain her sanity while fulfilling her sacred obligations. The documentary *Woody's Order!* captures the first time Ann performs portions of the play for its muse, Woody. Family legend has it that Ann was "ordered" into this world in 1957 by Woody, her then eight-year-old brother with severe cerebral palsy. Ann's destiny was to care for Woody if and when their parents could not. Woody was not expected to live past twelve. He lived to be almost 70. It has played to overwhelming acclaim in New York, Los Angeles, and Pittsburgh, the Talmans' hometown. She will show the film, and then welcomes Q&A from the audience.

- D. ***Choosing the Baby Carriage - Now What? The Journey of Parenthood and Experience of Sib-in-laws*** (Governors III)
Kristy Lynn Hartman, Co-Chair Sibs NY
Gary Arnold, Program Director, Progress Center for Independent Living

For many adult sibs, the choice to become a parent is a complicated subject. Although we now know of a number of factors as to why many siblings struggle with this decision, the question remains - what happens when you have made the choice to become a parent? What is the experience of telling your sibling with disabilities and your family that you will soon be starting your own? What is your expectation and desired outcome of these conversations and what happens in reality? What new concerns and fears now appear and how do you manage these emotions? How will life change not just for you, but for your sibling? And how do the sib-in-laws fit into this dynamic? What is their experience along this journey? What are their needs and how are they met? There is not a “What to Expect When You’re a Sibling and Expecting” book, but by siblings and siblings-in-law sharing personal experiences, a conversation opens up about the struggles and celebrations that come with deciding to be a parent. These conversations bring opportunities for support, and also opportunities to identify needs for further support and resources.

4:00 pm: Break

4:15 - 5:30 pm: Reception (Minnesota Ballroom)

Join us for a reception with hors d'oeuvres and refreshments (water and sodas included along with a cash bar.) This is a fun time to connect with other attendees and share sibling stories. There will be a silent auction with proceeds supporting the SLN, so bid away and have fun! Take time to look at the InFocus photography. Also, we are excited to present SLN’s first ever Lifetime Achievement Award to Don Meyer for his dedication to improving the lives of so many siblings of people with disabilities across the country and around the world.

5:30pm: Conference program concludes for the first day

Dinner on your own - feel free to connect with other Conference attendees and find a restaurant of your choice to enjoy dinner in St. Paul.

Sunday, June 23, 2019

8:00 am: Continental Breakfast (Minnesota Ballroom)

8:30 - 9:30 am: Table Talks (Minnesota Ballroom)

Select from the 10 topics listed below and participate in 2 rounds: 8:30-8:55 and 9:00-9:25

For each 25 minute session, please choose a topic and sit at the corresponding table for a rich discussion. Then move tables and switch to a second topic for the second round.

1. *Telling our story: Writing about siblinghood and disability*

Laura Rydberg, BA, MSW Candidate

It has been said that if we only concentrate on the relationship we do not have with our disabled sibling, then we run the risk of believing that we do not have the relationship that we think we should (Meltzer, 2018). This table talk explores how to uncover the relationship we do have--good, bad, and in-between--through stories and writing. An opportunity to write a story of your own sibling will be provided. The benefits of this exercise will also be explored.

2. *Transition Through The Years: The Life Of Jan*

Jane L. Lurquin, Ed. D.

Jan C. Lurquin

Presented by an adult with intellectual disabilities and her sibling to examine life transitions through the story of Jan, an individual with intellectual disabilities. To learn the quality of life model (Schalock, 2000) and learn how to enhance the quality of life so a person with intellectual disabilities can be successful in life. To understand the importance of creating links among individuals, families, school, and adult programs, so to determine how these components affect an individual's opportunities in life.

3. *Siblings of Children with Special Needs: Unique Concerns & Opportunities*

Emily Holl, Director, Sibling Support Project

Throughout their lives, brothers and sisters will share many—if not most—of the same concerns that parents of children with disabilities experience, as well as issues that are uniquely theirs. The sibling relationship is usually the longest-lasting relationship in a family. For the sake of everyone—brothers, sisters, parents, providers, and especially the family member who has a disability—siblings and their concerns must not be ignored. This table talk will provide an overview of common sibling concerns and opportunities, as well as sibling support strategies for lasting positive outcomes for the entire family.

4. *Self Advocacy Perspectives from Siblings with Disabilities*

Eric McVay, SLN Board member representing Self Advocates Becoming Empowered

The SLN includes siblings with and without disabilities. Come discuss the perspective of the sibling with disabilities. Learn more about Self Advocates Becoming Empowered (SABE) and ways to enhance advocacy and self-advocacy together.

5. *Diversity and Social Justice*

Alison Whyte, Executive Director, DC Developmental Disabilities Council

Siblings are keenly aware of the discrimination and negative attitudes that people with disabilities face and we have figured out all sorts of ways to advocate for better! At this table talk, we'll discuss how we can harness our natural advocacy skills as siblings for greater social justice for all people and be a truly inclusive movement of people with and without disabilities, people of all racial and ethnic backgrounds, all sexualities, all genders, all religions, all nationalities, and all shapes and sizes!

6. *Let's invite siblings to educational and service planning!*

Mayumi Hagiwara, PhD Candidate

This session will promote a discussion on how siblings can be part of educational and service planning for a sister/brother with significant support needs in school contexts and beyond. This presentation will guide participants' thoughts and ideas on how best to facilitate further family involvement and for that matter, sibling involvement, especially in the transition process. The focus of the discussion will be on Turnbull and colleagues' (2015) seven principles of effective family-professional partnerships: (1) communication, (2) professional competence, (3) respect, (4) commitment, (5) equality, (6) advocacy, and (7) trust.

7. *Siblings experiencing grief and loss*

Nora Handler, Board member Supporting Illinois Brothers and Sisters and Sibling Leadership Network
Shruti Tekwani, Licensed Mental Health Counselor

How can siblings support each other during times of grief? Siblings who have lost a brother or sister with disabilities often feel a unique and deep sense of grief. Traditional grief supports often don't feel like they fit for siblings.

8. *Self Advocacy Perspectives from Siblings with Disabilities*

Eric McVay, SLN Board member representing Self Advocates Becoming Empowered

The SLN includes siblings with and without disabilities. Come discuss the perspective of the sibling with disabilities. Learn more about Self Advocates Becoming Empowered (SABE) and ways to enhance advocacy and self-advocacy together.

9. *Club Sandwich Generation – Juggling Multiple Caregiving Roles*

Pat Carver, Founder, Community Drive, Inc. and MI SIBS
Meghan Burke, SLN Chair of Research Committee, Associate Professor of Special Education, University of Illinois at Urbana-Champaign

“The Sandwich Generation” is a term that is often used to describe people who are caring for their aging relatives and their own children. Adult siblings have an extra layer when they play a caregiving role for their sibling as well. Please join the conversation about the challenges and rewards of managing multiple caregiving roles.

10. Family Future Planning

Tamar Heller, Ph.D., Director, Institute on Disability and Human Development at the University of Illinois at Chicago

Tina M Campanella, CEO, Quality Trust for Individuals with Disabilities

Katie Arnold, SLN Executive Director

Planning for the future can be overwhelming for families, especially as parents age and siblings are often expected to take on greater support and caregiving roles. Come learn about resources and strategies to get the conversation started in your family to plan for the future in a way that each person can have a voice and a choice in the process.

9:45am Keynote Presentation (Minnesota Ballroom)

Generations: Sibling journeys, lessons, and triumphs across the years

Leah Alexander, Lynne Alexander Calloway, Alexander "Alex" Calloway, and Layci Calloway

As the philosophy for supporting people with disabilities has changed over time, so has the conversation we have as families. We no longer speak in whispers. We aspire to best lives, seek welcoming communities, and friendships. The area of sibling research and support, however, is only recently catching-up. Lynne Calloway is a sib, and the parent of two children. Her oldest child is also a sib. The Alexander-Calloway family will share their personal, generational sibling experiences against a backdrop of the civil rights movement, educational rights/advocacy, and the challenges of aging parents. The story will continue in the millennial voice with the triumphs and challenges of sibling relationships in the next generation. Both conversations will include lessons learned, surprising self-discoveries, and hopes for siblings in the future.

11:00 Using Charting the LifeCourse to Support our Siblings and Ourselves to Have a Good Life (Minnesota Ballroom)

Emma Shouse Garton, Public Information Specialist, Tennessee Council on Developmental Disabilities

Barbara Sapharas, Charting the LifeCourse National Team Member, Mentor Trainer, The Learning Community for Person Centered Practices, Independent Consultant

Alison Whyte, Executive Director, DC Developmental Disabilities Council

Charting the LifeCourse framework and principles were developed by families to support and empower people with disabilities and their families to develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Participants will begin to develop a Portfolio, identifying what makes a good life for their family member, possible resources and a description of their family member that focuses on WHO they are. Participants will also learn how they can use the Charting the LifeCourse planning tools for their own lives: to develop their own vision for a good life, plan steps toward self-care, problem solve and find support they need.

12: 00 Conference Concludes

***Thank you so much for joining us!
Please complete your evaluation to give us feedback.***

After the Conference

12:30 – 2:00 pm: Minnesota Sibling Chapter Leadership meeting

2:00 – 4:00 pm: Sibling Leadership Network Board Meeting

LIST OF PRESENTERS

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*Thank you to our SLN Conference Committee for
all of their great work to bring us together:*

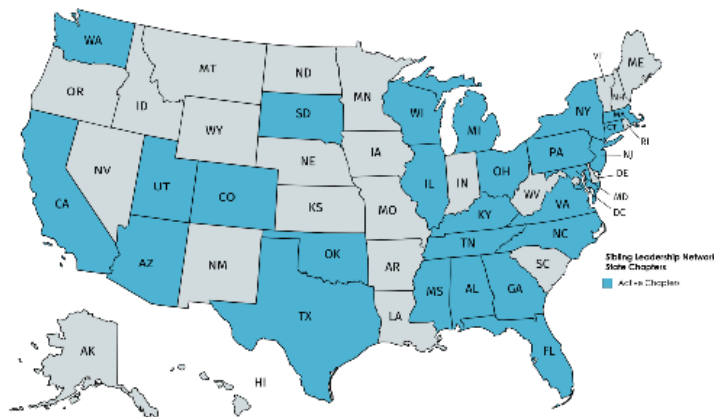
*Lindsey Polansky, Pat Carver, Amy Halm, Katie Arnold,
Lisa Matthews, Alex Jamieson, Sandra Tucker, Meghan
Hussey, Shruti Tekwani, Jessica Buettner, Mary Hayden,
Sara Hansen, and Ruth Lencowski.*

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Sara Hansen, Outgoing Chair (SD)
Emily Holl, Sibling Support Project Rep. (WA)
Eric McVay, SABE Representative (ME)
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HISTORY OF THE SLN

The SLN was founded in 2007 after seeing a need for more of a focus on siblings of people with disabilities. Here are highlights from over the years:

- **2007:** SLN was founded and held its first national conference in Washington, DC in November in conjunction with the Association of University Centers on Disability (AUCD) conference.
- **2008:** SLN held second national conference in Columbus, OH which culminated in the creation of a policy Whitepaper published with recommendations for research, advocacy and supports related to siblings.
- **2009:** A leadership meeting was held in Washington, DC in November and the first official Board of Directors was created for the SLN.
- **2010:** SLN incorporated as a nonprofit organization and also held an International Sibling Conference in Greenwich, CT.
- **2011:** A leadership meeting of the SLN Board was held in Nashville, TN where a strategic plan was developed for the future of the organization.
- **2012:** The SLN hired the first part-time Executive Director to grow the organization and a virtual leadership meeting of the Board was held.
- **2013:** The fourth National SLN Conference was held in Pittsburgh, PA in conjunction with the American Association on Intellectual and Developmental Disabilities (AAIDD).
- **2014:** SLN built organization structure and focused on chapter development, building partnerships, engaging members, and planning the 2015 Conference.
- **2015:** The fifth National SLN Conference was held in Louisville, KY in conjunction with AAIDD.
- **2016:** The SLN grew organizational capacity and hired a Communications Consultant and a Project Manager.
- **2017:** The SLN celebrates 10 year anniversary and holds sixth National SLN Conference in Hartford, CT.
- **2018:** SLN held a Multicultural Sibling Roundtable to highlight diversity of the sib experience.
- **2019:** The 7th National SLN Conference convenes in St. Paul, MN.