

NATIONAL SIBLING LEADERSHIP NETWORK CONFERENCE: Catching the Future



JUNE 6, 2013
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WELCOME

2013 NATIONAL SIBLING LEADERSHIP NETWORK CONFERENCE



Dear Friends and Colleagues,

I would like to personally welcome each of you to the 2013 National Sibling Leadership Network Conference: Catching the Future. It is an exciting time for the Sibling Leadership Network (SLN) as we continue to grow and partner with leading national organizations in the arena of disability to fulfill our mission of providing 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 families throughout the lifespan. There is an emerging recognition and respect nationally for the unique role that siblings play in the lives of people with disabilities and the contributions they make to the development and application of services and supports.

This conference is itself unique in its composition of attendees in that it brings together siblings of people with disabilities, self-advocates, parents and other family members, support professionals, and sibling supporters in mutual support, advocacy and inspiration. I would like to thank each of you for attending and bringing your story and expertise to our event. Your experiential knowledge and vision will support the SLN as we take hold of the future and pave the way for siblings of people with disabilities.

Sincerely,
Shea Tanis
Chair, SLN Board of Directors

Dear Siblings and Sibling Supporters,

As the first Executive Director of the SLN, I am so excited to welcome each of you to the National SLN Conference. It has been an amazing year of building and growing the organization along with a group of dedicated volunteers from across the country. The SLN Board and Committees have created such a powerful team that is passionate about the mission and values of the organization.

We believe:

- Individuals with disabilities have the same rights as all members of society to dignity, respect and the opportunity to grow and to be productive members of their communities.
- Siblings of individuals with disabilities can have a powerful, positive impact on their siblings' experiences, and are uniquely positioned to help ensure their present and future care in partnership with service organizations and government.
- In promoting the rights of our brothers and sisters, and of all individuals with disabilities, we are committed to advocating for policies and services that meet their needs.
- Siblings can be of great support to one another to enhance both our lives and the lives of our siblings.



I hope your time at our conference fills you with knowledge, understanding, connections with great people, and a sense that you are part of a larger movement.

Best,
Katie Arnold
Executive Director, SLN

The Sibling Leadership Network (SLN) is a national nonprofit with state chapters dedicated to providing 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.

CONFERENCE SCHEDULE

8:30 am Registration and breakfast

9:00 am Welcome and Introductions

*Speakers: **Lynne Mack** (Pennsylvania Sibling Support Network) & **Shea Tanis** (Chair of SLN)*

9:30 am Power of Storytelling

Learn the importance of telling our individual and collective stories as siblings and sibling supporters. Practice sharing your story and listening to others.

*Speakers: **Barb Sapharas** (Ohio SIBS), **Pat Carver** (SLN Vice Chair & Michigan SIBS), **John Kramer** (SLN Outgoing Chair & Massachusetts Sibling Support Network), & **Angela Martin** (SLN Secretary & Michigan SIBS)*

11:00 am Break

11:15 am Research Panel

Hear about the latest in research about siblings of people with disabilities.

*Speakers: **Tamar Heller** (SLN Treasurer) & **Jed Johnson** (Easter Seals)*

12:00 pm Lunch buffet

Enjoy lunch while networking -- change tables and talk to new people.

Research Roundtable with Risa Matsumoto: Hear about Risa's research comparing the experience of siblings in the US and Japan.

12:45 pm Sibling Experiences Video

CONFERENCE SCHEDULE

- 1:00 pm **Supports and Resources across the Lifespan**
Learn about the different types of supports and resources siblings need throughout their lives.
*Speakers: **Don Meyer** (Sibling Support Project), **Tom Fish** (Ohio SIBS), & **Kristin Lanari** (Fox Valley Sibling Support Network)*
- 2:00 pm **SLN Activities and Sibling Engagement**
Find out ways to get involved in the activities of the national Sibling Leadership Network.
*Speaker: **Katie Arnold** (SLN Executive Director)*
- 2:30 pm **Break**
- 2:45 pm **National Perspectives**
Hear from national experts on how they are involving siblings in their work.
*Speakers: **Maggie Nygren** (AAIDD), **Nancy Thaler** (NASDDDS), **Hillary Spears** (NACDD) & **Kim Musheno** (AUCD)*
- 3:45 pm **Civil Rights, Self-Determination, and Empowering Siblings**
Learn ways to empower siblings to ensure civil rights and increase self-determination.
*Speakers: **Eric McVay** (SABE) & **Barb Sapharas** (Ohio SIBS)*
- 4:15 pm **Wrap up and conclusion**
*Speaker: **Shea Tanis** (SLN Chair)*
- 5:00 pm **Conclude**

SPEAKERS



Katie Arnold is the Executive Director of the Sibling Leadership Network. Katie has been involved in the SLN since the organization's inception in 2007 and became the first Board Chair in 2010. At the state level, she has been a leader of the SLN chapter SIBS-Supporting Illinois Brothers and Sisters. Her Masters in Disability and Human Development is from the University of Illinois at Chicago. Also, Katie works as the Director of Community Education in the Institute on Disability and Human Development. She serves on a number of boards including the Council on Quality and Leadership and AUCD's Family Support Special Interest Group. Her work is anchored to her experience growing up with her sister with intellectual disabilities.



Pat Carver is the Vice Chair of the Sibling Leadership Network and co-founder of MISIBS, a network of brothers and sisters in Michigan. She brings a lifetime of heartfelt commitment to her work which began five decades ago at the birth of her brother and the subsequent recognition that his being "special" meant being set apart. Since then Pat has relentlessly advocated for social justice, especially among citizens who experience cognitive or intellectual disabilities. Pat leads the communications effort at the Michigan Partners for Freedom and facilitates Community Drive, Inc., a knowledge based practice dedicated to building circles of support, community connection training, curriculum development and consultation: www.communitydrive.org. Pat is skilled at person-centered planning, supporting the importance of belonging, creating support circles and strengthening individual capacities to create community.



Tom Fish, Ph.D., is a founding member of Ohio SIBS and the National Sibling Leadership Network and currently serves as the SLN's Chair of Services and Supports. Tom is the Director of Social Work at The Ohio State University Nisonger Center where he oversees family/sibling support, adult literacy, community inclusion, autism, and school-to-work transition. He has authored two books and several professional journal articles. Tom is also the founder of the Next Chapter Book Club, a community-based literacy and friendship program which has over 225 clubs across the US and in four other countries. Dr. Fish is a AAIDD Fellow and a past recipient of a Mary Switzer Research Fellowship from NIDRR.



Tamar Heller, Ph.D., is a founder of the Sibling Leadership Network and currently serves as the SLN Treasurer. Tamar is Professor and Head of the Department of Disability and Human Development, University of Illinois at Chicago and director of its University Center of Excellence in Developmental Disabilities and its Leadership Education in Neurodevelopmental and related Disabilities program. She also directs the Institute's Rehabilitation Research and Training Center on Lifespan Health and Function, Family Clinics, and TAP autism program. Her current research focuses on self-directed and family supports, managed care, and health promotion interventions for individuals with disabilities. Dr. Heller has written over 200 publications, including 5 books.



Jed D. Johnson is Director of National Veteran Caregiver Training Program for Easter Seals. For 8 years, Jed provided strategic leadership for Easter Seals' services for adults and seniors. From 2008-2011 he served as Director of the National Center on Senior Transportation. Previously Jed spent 10 years of progressive responsibility with the Jewish Association on Aging in Pittsburgh. Jed has served as Treasurer of the American Society on Aging and as a member of Generations United's program and intergenerational shared site committees. He is a member of the National MS Society's Long Term Care clinical advisory board and is a CARF surveyor for the accreditation process within their Aging Services division. Jed holds a joint-masters degree in business administration from the Wharton School of Business and in social work from the University of Pennsylvania's School of Social Policy and Practice.

SPEAKERS



John Kramer, Ph.D., is a founder of the Massachusetts Sibling Support Network (MSSN), Supporting Illinois Brothers and Sisters, and the Sibling Leadership Network where he currently serves on the Executive Committee. John earned his PhD in disability studies while working in the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago. John works at the Institute for Community Inclusion (ICI) where he is currently working on the state systems research and evaluation team. From 2011–2012, he was awarded a Switzer research fellowship from the NIDRR where he examined the roles that siblings play in supporting employment for people with intellectual and developmental disabilities.



Kristin Lanari is a board member and fundraising chair for the Fox Valley Sibling Support Network, the Wisconsin chapter of the Sibling Leadership Network. Kristin uses her creative talents to capture people with disabilities in photographs (including her sister Lauren who has Down syndrome) and promote awareness of sibling issues. Kristin and her husband Tom own Lanari Photography in Appleton, Wisconsin, and have had the honor to photograph many siblings over the years. In 2009, she received a grant from the Wisconsin Board for People with Developmental Disabilities to create a book entitled Walk With Me, featuring essays by people who have siblings with Down syndrome.



Lynne Mack is founder of the Pennsylvania Sibling Support Network. She is a long time advocate for her sister Diona. Lynne has held many positions over the years including Sgt. in the United States Air Force in Miami Florida, social worker for the city of Philadelphia, and certified investigator and advocate for individuals with disabilities. Lynne is also the president and CEO of Agatha Carr Publishing House and has published three of her own books. Lynne began speaking publicly about her private family issues concerning being a caregiver for her mother who had developed Alzheimer's and stepping into the role of primary caregiver for her sister. She developed an internet radio show, The Lynne Mack Show, with weekly discussions about caring for someone with a disability and an aging parent. She has also spoken at support groups and around the Philadelphia area and participated in panels for siblings of individuals with disabilities.



Angela Martin is Secretary of the Sibling Leadership Network and founder of MISIBS in Michigan. She is a Community Support Specialist/Research Assistant with the Developmental Disabilities Institute at Wayne State University in Detroit, Michigan. Angela has a Master's degree in Social Work with a concentration in Community Practice and Social Action. She has experience in family support resource development and curriculum design and training of programs on Self-Determination, Person Centered Planning, and Leadership/Self-Advocacy. Angela's youngest sibling, who was born with intellectual and development disabilities over 20 years ago, has laid a strong foundation in her life's work particularly as it relates to Self-Determination. As a founding member of Michigan Partners for Freedom, Angela has been involved in building statewide demand for Self-Determination.

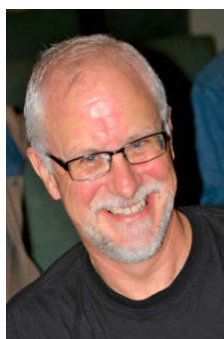


Risa Matsumoto is a researcher doing research comparing the experience of siblings in the US and Japan. Risa is a joint organizer of Shirokuma-Kai (White Bear Group), a sibling group for people in their 20s and 30s. Risa is a facilitator for Nakayoshi-Kai (Kids-Getting-Along Group) which is a recreational group for sibling children. She also received Sibshops Training in Ohio and is a member of the Kyoto chapter of the Society for Siblings of People with Disabilities. Risa is currently working towards her Ph.D. at Doshisha University Graduate School of Social Welfare in Kyoto, Japan. In addition to being a Research Fellow of the Japan Society for the Promotion of Science, she teaches Social Work for People with Disabilities part-time at Ryukoku University. Her research is influenced by her experience having a brother with intellectual and developmental disabilities.

SPEAKERS



Eric McVay is a board member of the Sibling Leadership Network and a member of Self Advocates Becoming Empowered (SABE), the national self-advocacy organization for people with developmental disabilities. He is also an active member of his state self-advocacy organization in Maine called Speaking Up For Us. Eric is also part of the Consumer Council System of Maine, a voice for consumers of mental health services. He is active in advocacy and knowledgeable about policies that impact people with disabilities. Eric lives in his family home in Maine. He has a close relationship with his older sister.



Don Meyer is a board member of the Sibling Leadership Network and the director of the Sibling Support Project, a national effort dedicated to the interests of millions of brothers and sisters of people with special health, developmental, and mental health concerns. As the project's director, Don has conducted more than 300 workshops in all 50 states as well as eight countries. His workshops and trainings have reached thousands of parents and providers have helped establish more than 400 Sibshops worldwide. Don was a founder of the Supporting Extended Family Members program at the University of Washington, which pioneered services for fathers, siblings, and grandparents of children with special needs. SibKids, SibTeen, and SibNet--the Yahoogroups and Facebook groups Don created for young, teen, and adult siblings--connect thousands of brothers and sisters with their peers every day. In 2012, he created GKSIN (Grandparents of Kids with Special Needs) to connect grandparents with their peers.



Kim Musheno is the Director of Legislative Affairs at the Association of University Centers on Disabilities where she works on federal policy and legislative issues that affect people with developmental disabilities and their families. She also provides leadership representing AUCD on the Consortium for Citizens with Disabilities (CCD) Board of Directors, a coalition of more than 100 national disability organizations. Kim co-chairs the CCD Task Forces working on Fiscal policy, developmental disabilities, and Autism, and serves on the Health and Long Term Services Task Forces. Prior to working at AUCD, Kim was a communications specialist at The Arc of the United States Governmental Affairs Office and research assistant at the National Association of Councils on Developmental Disabilities (NACDD). During her approximately 20 years working in the field of disability policy, Kim has monitored or worked on nearly every major piece of legislation that affects people with developmental disabilities and their families.



Margaret Nygren, Ed.D., is the Executive Director of AAIDD, the oldest and largest interdisciplinary organization of professionals and others concerned about intellectual and related disabilities. Her previous positions include Associate Executive Director for Program Development at the Association of University Centers on Disabilities (AUCD), a Fellowship in the Disabled and Elderly Health Programs Group at the Centers for Medicare and Medicaid Services (CMS), and Director of the Center on Aging and Disabilities at the Lieutenant Joseph P. Kennedy Institute. She earned a Doctorate of Education in Organizational Leadership from Nova Southeastern University, a MA in Clinical Psychology from West Virginia University, and a BA in Psychology from Beloit College.

SPEAKERS



Barb Sapharas is Chair of Ohio SIBS, the Ohio chapter of the Sibling Leadership Network. She has worked in the field of Developmental Disabilities for over 37 years in a variety of positions including Speech Language Pathologist, Staff Development Specialist, Support Administrator/Case Coordinator, and is an Adjunct Professor at Notre Dame College. Over the years, Barb has developed and provided training nationally on a variety of topics including; communication, rights, person centered thinking and planning, informed decision making and consent, and group facilitation. Barb is also a Mentor Trainer in the Learning Community for Person Centered Practices chaired by Michael Smull. She has two brothers. Her youngest brother, Nick, had Cerebral Palsy and passed away at the age of 45. Her life experience as a sibling has promoted her passion for supporting people to have their own “voice” and be heard in all aspects of their life.



Hillary Knapp Spears is the Director of Training and Technical Assistance at the National Association of Councils on Developmental Disabilities. Prior to joining NACDD, Hillary worked at the Association of University Centers on Disabilities (AUCD) coordinating the Administration on Intellectual and Developmental Disabilities’ Envisioning the Future: Allies in Self-Advocacy Summits. Hillary holds a MSW and a M.A. in Public Policy and Administration degree from The Ohio State University. While completing her Master degrees she trained as a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) fellow at The Nisonger Center. Throughout her career Hillary has actively worked to promote disability rights through experiences at the Ohio House of Representatives, Advocacy and Protective Services, Inc., Aspirations Ohio and at the US Senate.



Shea Tanis is Chair of the Sibling Leadership Network. She is an Instructor/Fellow in the Department of Psychiatry and Coleman Institute for Cognitive Disabilities at the University of Colorado. She serves as the Research Coordinator for the State of the States in Developmental Disabilities Project which investigates the determinants of public spending for Intellectual and Developmental Disability Services in the United States. She is a doctoral candidate at the University of Kansas in the Department of Special Education, where she was the recipient of a leadership fellowship at the Beach Center on Disability. She is also Co-PI of an Office of Special Education funded Steppingstones of Technology Innovation for Children with Disabilities, a subcontract from the University of Kansas. Shea is the sister to one of her greatest inspirations, her brother who just happens to have a traumatic brain injury.



Nancy Thaler is the Executive Director of the National Association of State Directors of Developmental Disabilities Services. The Association provides member state agencies with analyses of federal statutory and regulatory policies that affect people with disabilities; disseminates information on state-of-the-art programs and service delivery practices; provides technical assistance and support to member states; and offers a forum for the development of state and national policy initiatives. Ms. Thaler served as Pennsylvania’s Deputy Secretary for Mental Retardation from 1993-2003 managing a system that served over 80,000 children and adults. Ms. Thaler also worked for the Federal Center for Medicare and Medicaid Services (CMS) from 2003-2006 and was responsible for the quality improvement strategy for the Federal Medicaid Home and Community-Based Waiver Program. Ms. Thaler a Master of Human Organization Science with a specialty in public administration from Villanova University. Ms. Thaler is the parent of an adult son with cognitive disabilities.

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siblings INITIATIVE

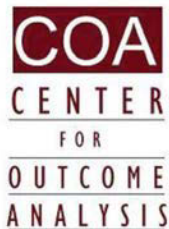
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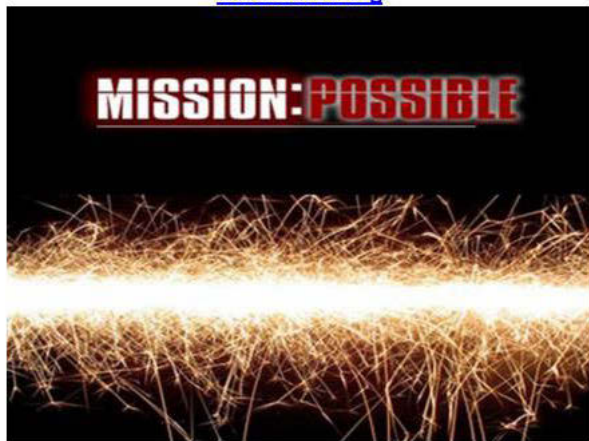
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A very big thank you to the SLN'S Conference Committee
for all their planning and hard work!

Katie Arnold
Pat Carver
Tamar Heller
John Kramer
Lynne Mack
Barb Sapharas
Shea Tanis

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