Making a Difference Together

2015 NATIONAL SIBLING LEADERSHIP NETWORK CONFERENCE

May 30-31st, 2015

Galt House Hotel
Louisville, KY
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.
WELCOME FROM THE SLN BOARD CHAIR

Hello Everyone,

On behalf of the Board and the Conference Committee, I want to welcome you to our 5th Sibling Leadership Network (SLN) Conference! We are very pleased to be in Louisville, Kentucky.

I want to thank the Conference Committee and our Executive Director, Katie Arnold, for all their enthusiasm and work over the last year. We have attendees from different parts of the country and spanning three generations. As different as we are, we share a common experience and focus—to promote issues of concern and advocate with our brothers and sisters. We have a program that we think will inform and inspire.

We hope that you will take advantage of this time together to network and connect with others! We have an active network on social media. The Conference provides us with an opportunity to meet those we only know online and to reconnect with others.

The SLN has been very busy this past year, supporting states to develop chapters growing from 13 to 19 states. We have also developed new collaborative relationships as well as enhancing current relationships. As we are growing and evolving as an organization, we took time to strengthen our structure.

Nationally, there is a lot of change occurring in the supports for people with disabilities and their families. There is a greater recognition and inclusion of siblings at the national and state levels and you will hear about some of those activities.

I want to thank each and every one of you for attending our 5th Conference. We hope that you will leave the Conference with information, resources, and friendships that will provide you with support as you return home.

I look forward to meeting you all, sharing and learning together!

Barb Sapharas
A SPECIAL THANKS TO OUR SPONSORS

SUPER DUPER SIB LEVEL:
Commonwealth Council on Developmental Disabilities

SUPER SIBLING LEVEL:
American Association on Intellectual and Developmental Disabilities
Coleman Institute for Cognitive Disabilities
EasterSeals and MassMutual
Institute on Disability and Human Development at the University of Illinois at Chicago
The Arc

BIG SIB LEVEL:
American Network of Community Options and Resources
Human Services Research Institute
National Association of Councils on Developmental Disabilities

MIDDLE KID LEVEL:
A good friend of the SLN
Cedar Lake
Lee Specialty Clinic
National Leadership Consortium on Developmental Disabilities
Quality Trust and The National Resource Center for Supported Decision-Making

YOUNGER SIB:
Community Drive
Developmental Disabilities Institute at Wayne State University
Human Development Institute at the University of Kentucky

SPONSOR A SIB LEVEL:
Center for Outcome Analysis
Nora and Bruce Handler
Supporting Illinois Brothers and Sisters

A special thanks to our SLN 2015 Conference Committee for all their work to bring us all together!
BRIEF HISTORY OF THE SLN:

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 its second national conference in October 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 in January.

2013  The fourth National SLN Conference was held in Pittsburgh, PA in conjunction with the American Association on Intellectual and Developmental Disabilities (AAIDD).

2013  SLN’s Executive Board met in Chicago to identify focus for the future including Chapter Development and building internal capacity.

2014  SLN focused on chapter development, building partnerships, committee work, organizational development and capacity building.

2015  The fifth National SLN Conference held in Louisville, KY in conjunction with AAIDD.
Making a Difference Together
<table>
<thead>
<tr>
<th>TIME</th>
<th>ACTIVITY</th>
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<tbody>
<tr>
<td>11:30am</td>
<td>Registration and Lunch (Provided)</td>
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<tr>
<td>12:30pm</td>
<td>Welcome and Introductions</td>
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<tr>
<td></td>
<td>Speakers: Barb Sapharas (SLN Board Chair), Jessica Marschke (KY Sibling Leader), &amp; Maggie Nygren (AAIDD Executive Director)</td>
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<tr>
<td>1:00pm</td>
<td>Making a Difference Through Storytelling</td>
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<td>Speaker: Pat Carver (SLN Outgoing Board Chair)</td>
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<td>1:15pm</td>
<td>Dare Mighty Things</td>
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<td>Featured Speaker: Tori McClure (President of Spalding University)</td>
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<td>1:45pm</td>
<td>BREAK</td>
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<tr>
<td>2:00pm</td>
<td>Stories from a Panel of Siblings</td>
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<td>Moderated by Don Meyer (Executive Director, Sibling Support Project)</td>
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<tr>
<td>3:00pm</td>
<td>Sharing Sibling Stories: Table Discussions</td>
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<tr>
<td>3:45pm</td>
<td>BREAK and Continue Sharing Stories at Tables</td>
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<td>4:00pm</td>
<td>Public Administrator, Advocate, Sibling:</td>
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<td>Who Am I? Who I Am.</td>
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<td>Featured Keynote: Andrew McQuaide (Consent Decree and Settlement Agreement Coordinator for the State of Rhode Island)</td>
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<td>5:00pm</td>
<td>The Sibling Movement and the SLN</td>
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<td>Speaker: Katie Arnold (SLN Executive Director)</td>
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<td>5:30pm</td>
<td>Program Concludes for the Day*</td>
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<td>* Dinner on your own (Feel free to connect with other conference attendees and find a restaurant of your choice to enjoy dinner.)</td>
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<td>7:30pm</td>
<td>SPECIAL EVENT:</td>
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<td>Sibling Survival Guide Book Signing Reception</td>
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<td>Featuring Editor Don Meyer</td>
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<td>Join us for an evening of networking with other attendees.</td>
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<td>Bring or purchase copies of the Sibling Survival Guide and get it signed by the Editor and Authors.</td>
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<tr>
<td>7:30am</td>
<td>Breakfast (Provided)</td>
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<td>8:00am</td>
<td>Charting Your LifeCourse Towards a Good Life!</td>
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<td><strong>Featured Keynote:</strong> Sheli Reynolds (Director of Individual Advocacy and Family Support at UMKC Institute for Human Development)</td>
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<td>9:00am</td>
<td>BREAK</td>
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<td>9:10am</td>
<td><strong>Breakout Sessions 1</strong> (Choose ONE of the Following):</td>
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<td>A.</td>
<td><strong>Planning for the Future: The Sibling Roadmap</strong></td>
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<td><strong>Speakers:</strong> Katie Arnold (SLN Executive Director) and Liz Mahar (Program Manager, The Arc’s Center for Future Planning)</td>
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<td>Hear from two siblings about the areas to think about when planning for the future with your whole family. You will learn about how to get the difficult dialogue started in your family, the process of future planning, and an overview of the areas that are important to consider for planning. Resources will be shared that can help families plan and navigate the process, including information on The Arc’s Center for Future Planning.</td>
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<td>B.</td>
<td><strong>Translating Research into Advocacy for Siblings of Individuals with Disabilities</strong></td>
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<td><strong>Speakers:</strong> Meghan Burke (SLN Chair of Research), Tom Fish (SLN Chair of Support &amp; Information), Kristina Majewski (SLN Chair of Policy &amp; Advocacy), &amp; Shea Tanis (SLN Past Chair)</td>
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<td>In this session, we will discuss the connection between research and advocacy as well as ways that individuals can conduct advocacy for siblings of individuals with disabilities. We will begin by briefly describing the existing state of research that pertains to siblings of individuals with disabilities, including studies about caregiving roles, sibling relationships, and future planning. We will then consider the implications of existing research on local and national advocacy. We will highlight key advocacy efforts and ways in which individuals can get involved. We will conclude with a discussion about effective advocacy strategies.</td>
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<td>C.</td>
<td><strong>Supporting Self-Determination</strong></td>
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<td><strong>Speakers:</strong> Rachel Patterson (SLN Communications Co-Chair), Pat Carver (SLN Outgoing Chair), and Liz Weintraub (Advocacy Specialist at AUCD)</td>
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<td>People with disabilities too often lack control over their own lives. This session will explore self-determination from personal and sibling’s perspectives, including how sibs can help their brothers and sisters with disabilities increase their own self-determination and how supporting self-determination can improve quality of life for the whole family.</td>
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<tr>
<td>10:10am</td>
<td>BREAK</td>
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TIME ACTIVITY
10:20am Breakout Sessions 2 (Choose ONE of the Following):
A. Wills, Trusts, Power of Attorney—Oh My! Legal Documents Needed to Safeguard Your Sibling’s Future
   Speakers: Karen Perch (Attorney at Law) and Carolyn Wheeler (Project Director, Human Development Institute/University of KY)

Creating and sustaining a safe and secure future for a person with a disability is of paramount concern for many families. Having legal authority to assist with decision making, applying for publicly funded resources, managing finances and advocating for or with a loved one is a critical component to ensuring a life of dignity and respect. If estate planning is not done correctly a person’s eligibility for publicly funded services could be jeopardized. Using actual people from the presenters’ experience, the differences between guardianship, durable power of attorney, and advanced directives as well as the role of a will, special needs and supplemental needs trusts will be described.

B. Developing Your Sibling Chapter
   Speakers: Nora Handler (Supporting Illinois Brothers and Sisters), Harriet Redman (Executive Director of WisconSibs), and Erin Sweeney Hutzelman (SLN Chair of Network Development)

In this session you will learn from founding members of state chapters about how to start and grow your own chapter. If you are looking to start a chapter or expand its reach this session is for you. Learn what has worked for other chapters and what the speakers learned from other non-profit organizations. Highlights from the new Chapter Development Guide will be presented.

C. We are Family: Understanding the Collective Family Voice
   Speakers: Shea Tanis (SLN Past Chair), Eric McVay (SABE rep on SLN Board), Debbie Gilbert (Co-Director, Family to Family Health Information Centers) and Tia Neils (President of SABE)

Supporting families of people with cognitive disabilities includes understanding the unique perspectives of not only the person with the disability, but also parents, and siblings. Nationally, self-advocates, parents, and siblings have partnered to bring a collective voice to advocacy for people with cognitive disabilities. This presentation will demonstrate the unique voice of each of the family perspectives in interpreting the impact and future of supports and services for all members of the family constellation.

11:20am BREAK
11:30am Closing Session and Open Mic
12:00pm Conference Concludes
MICHELLE “SHELI” REYNOLDS

My passion, knowledge and experience come from growing up as a sibling of a younger brother with developmental disabilities. For the last 17 years I have served as the Director of Individual Advocacy and Family Support at UMKC Institute for Human Development, a University Center on Excellence in Developmental Disabilities where I am directly responsible for projects that directly impact the lives of persons with disabilities and their families through both policy and practice changes. I am currently the Director of the Missouri Family to Family Health Information Center and the co-principle investigator on the National Community of Practice on Supports to Families. This year I was appointed as a member of the Presidents Committee for People with Intellectual Disabilities. For twelve years I had the privilege of providing technical assistance to the self-advocacy organizations for Missouri and the nation, which served as my biggest training ground. I received my doctorate in Public Administration and Sociology from the University of Missouri, Kansas City with a focus on family support research and policy for families of individuals with developmental disabilities across the lifespan.

ANDREW MCQUAIDE

In August of 2013, Andrew joined the State of Rhode Island as Coordinator of Community Development and Planning for the Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals. Through administration of the Department’s Employment First policy and the US Department of Justice Interim Settlement Agreement, Andrew facilitates greater access to community-based, integrated employment and day services for individuals with intellectual and/or developmental disabilities. In November 2013, Andrew was appointed the Rhode Island State Coordinator of the US Department of Justice Interim Settlement Agreement. In this role, Andrew coordinates and supports interagency collaboration between the Rhode Island Department of Behavioral Healthcare, Developmental Disabilities & Hospitals, Office of Rehabilitation Services, and the Rhode Island Department of Education in their implementation of the settlement agreement. Most recently, Andrew helped facilitate the landmark agreement between the State of Rhode Island and the DOJ. In April 2014, Governor Lincoln Chafee appointed Andrew Consent Decree Coordinator.
TORI MCCLURE
Tori Murden McClure is the president of Spalding University, in Louisville, Kentucky, which serves more than 2,500 students at the bachelor’s, master’s and doctoral levels. Tori holds a Bachelor of Arts from Smith College, a Master of Divinity from Harvard University, and her juris doctorate from the University of Louisville’s Louis D. Brandeis School of Law. In 2005, she earned her master of fine arts in writing from Spalding University. Her non-fiction book A Pearl in the Storm was published by Harper-Collins in 2009. A passionate world adventurer and humanitarian, Ms. McClure is best known as the first woman and first American to row solo across the Atlantic Ocean. She was also the first woman and first American to travel over land to the geographic South Pole, skiing 750 miles from the ice shelf to the pole. An avid mountaineer, Ms. McClure has climbed on several continents. She is a fully certified emergency medical technician in both urban and wilderness areas, and is a graduate of the National Outdoor Leadership School (NOLS) where she currently serves as the chair of the board of directors. Tori Murden McClure is the Legal Guardian for her brother with an intellectual disability, Lamar Murden.

FUN FACTS ABOUT THE SLN:
• The SLN has over 4,000 members across the country.
• There are currently 19 sibling chapters in states with the vision that every state will have an SLN chapter in the future.
• 5 Committees of the SLN are ways for people to get involved.
• Joining the SLN is free and easy—just sign up at www.siblingleadership.org
PRESENTERS

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Past Chair,
Sibling Leadership Network
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Tom Fish
Chair of Support & Information,
Sibling Leadership Network
Email: Thomas.fish@osumc.edu
SLN BOARD OF DIRECTORS

Barb Sapharas, Chair (OH)
David Horton, Vice Chair (TX)
Pat Carver, Outgoing Chair (MI)
Tamar Heller, Treasurer (IL)
Angela Martin, Secretary (MI)
Eric McVay, SABE Representative (ME)
Renee Frederick, Claire Nuchtern, and Ellie Rosenthal, Sibs’ Journey Reps
Kristina Majewski, Chair of Policy & Advocacy (DC)
Alison Whyte, Co-Chair of Policy & Advocacy (DC)
Tom Fish, Chair of Support & Information (OH)
Edward O’Neil, Co-Chair of Support & Information (TX)
Meghan Burke, Chair of Research (IL)
Caya Chiu, Co-Chair of Research (Taiwan)
Rachel Patterson, Chair of Communications Committee (DC)
Deirdre O’Connor, Co-Chair of Communications (NY)
Erin Hutzelman, Chair of Network Development (OH)
Nora Handler, Chapter Rep. (IL)
Katie Arnold, Executive Director (IL)

SLN CHAPTER REPRESENTATIVES

AL-Wynona Raby
CA-Julie Neward
CO-Sandra Tucker
DC-Rachel Patterson
GA-Nick Perry
IL-Nora Handler
MA-Cindy Haddad
MD-Carolyn Chen
MI-Jennifer McFarlane
MN-Jeremy Warring
NH-undergoing leadership change
NJ-Kara Sellix
NY-Lindsay Hyland
OH-Sarah Hall
PA-Lynne Mack
TN-Emma Shouse
UT-Amy Notwell
VA-Dana Yarbrough
WI-Kristin Lanari

SLN 2015 CONFERENCE COMMITTEE

Katie Arnold (IL)
Pat Carver (MI)
Sylvia Collazo (FL)
Patty Dempsey (KY)
Sarah Hall (OH)
Jessica Marschke (KY)
Eric McVay (ME)
Linda Monterroso (NY)
Rachel Patterson (DC)
Deirdre O’Connor (NY)
Lex Owen (IL)
Barb Sapharas (OH)
Shea Tanis (CO)
Carol Ann Tudor (KY)
Liz Weintraub (DC)
Carolyn Wheeler (KY)
Mona Wilkerson (KY)
The Commonwealth Council on Developmental Disabilities is a dynamic mix of people with unique backgrounds and experiences. Members include 16 governor-appointed individuals with disabilities and family members of individuals with disabilities, as well as representatives from major state agencies that serve people with developmental disabilities.

Get Involved Today
Advocate... Volunteer... Provide Support
And consider joining the CCDD Council
Info: (877) 367-5332 or visit www.kyccdd.com
At Easter Seals, we believe our community is stronger when we build on the abilities of all of our neighbors. That’s why we work, day in and day out, in local communities to champion ability. We pave the way with programs, services and advocacy to advance the potential of each person we serve, and the families who love them. Whether it is supporting a sibling with special needs, caring for a son or daughter living with autism, an aging parent with Alzheimer’s or dementia, or a new veteran returning home, Easter Seals is there.

Easter Seals and Mass Mutual Financial Group are partnering to change the national conversation about family caregiving with our “Many Faces of Caregiving Study” focused on Millennials and Gen-Xers. To learn more and download findings visit: easterseals.com/carestudy

- 70% of Millennials and Gen-Xers expect that they will likely be providing care to a loved one, only 51% feel ready to step into the role
- Millennials and Gen-Xers are looking for information and understanding to help plan for the future (financial, available services & what to expect)
- Over 2/3 of Millennials and Gen-Xers currently providing caregiving support enjoy the closer relationship formed, but some express stressors and challenges
FEATURING KEYNOTE SPEAKER
Timothy P. Shriver, Ph.D.
Chairman of Special Olympics, co-founder and chair of the Collaborative for Academic, Social and Emotional Learning (CASEL) and best-selling author of *Fully Alive: Discovering What Matters Most*.

WHEN: Thursday, October 15, 2015
WHERE: Omni Interlocken Hotel
500 Interlocken Blvd.
Broomfield, CO 80021
REGISTER NOW: www.colemaninstitute.org
Email: ColemanInstitute@cu.edu

PARTNER EVENT
ANCOR Technology Showcase

Conference Co-Sponsors

Coleman Institute for Cognitive Disabilities
UNIVERSITY OF COLORADO

University of Colorado Office of the President
3825 Iris Avenue, Suite 200, Boulder, CO 80301
303-492-0639 | ColemanInstitute@cu.edu
www.colemaninstitute.org
The Center provides reliable information and assistance in these areas to individuals with I/DD, their family members and friends, support professionals and the community:

- person-centered planning
- decision-making
- housing options
- financial planning

For more information please visit futureplanning.thearc.org
WHY ARE SIBS IMPORTANT?

- Siblings have the longest-lasting familial relationships.
- Siblings often become the next generation of supporters and caregivers when parents are unable to provide care.
- Even though siblings have unique roles and are likely future caregivers, the needs and perspectives of siblings are often overlooked.
- Siblings are referred to as the “club sandwich generation” because they often juggle the caregiving of their aging parents, their own children, as well as their brothers and sisters with disabilities.
- By addressing the needs of siblings, their brothers and sisters with disabilities are likely to have better outcomes.
Using rigorous data collection, evaluation, and performance measurement, HSRI helps agencies tailor their service systems to better meet the changing, complex health needs of communities and constituents.

An early advocate for actively surveying and engaging service users, HSRI has a long history of working with consumers and their families to establish and promote meaningful outcomes.

As a nonprofit, HSRI focuses solely on addressing some of the most pressing issues for individual and community well-being: child welfare, developmental and physical disabilities, substance abuse, and mental health.

Working to improve health & human services and service delivery for nearly 40 years

www.hsri.org
CONGRATULATIONS
TO THE
2015 NATIONAL & STATE RECIPIENTS
OF THE
ANCOR
Direct Support Professional Recognition Awards

We look forward to “Direct Support Professional Recognition Week” September 13-19, 2015

SAVE THE DATE!
2015 ANCOR Technology Summit & Showcase · October 15 - 16 · Broomfield, CO
Held in conjunction with the Coleman Institute 15th Annual Conference: Inequality and the Rights of People with Cognitive Disabilities to Technology and Information Access

Human Development Institute
“Changing Practice, Changing Lives”

HDI provides a broad set of projects and programs across the life span to improve services for individuals with disabilities and their families.

- State and national initiatives focused on communication competence for students with the most significant disabilities
- Programs for school districts to improve transition services and post-school outcomes for youth and young adults with disabilities
- Training for adult service agencies in supported employment, health and wellness, and full community participation
- Post-secondary and college opportunities for students with intellectual disabilities
- Our Graduate Certificate in Developmental Disabilities, offered both on-campus and on-line
- Our Fall and Spring Statewide Seminar Series

For more information on our programs, visit us online www.hdi.uky.edu

The “CONVERSATION”

Has your family had it?
Where do you start?
How do you start?

Talking about the day when your parents will no longer be able to care for your sibling is difficult. Let us help your family begin the conversation!

The Adult Sibling Toolkit™ is available for download and printing at no charge from our website:
www.ndsccenter.org/resources/adult-sibling-toolkit/

It can be shipped free to NDSC member families (one per household) or $10 for non-members. Call to order – 800-232-6372

NATIONAL DOWN SYNDROME CONGRESS
Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium on Developmental Disabilities, along with major developmental disability organizations, offers intensive week-long trainings for emerging leaders in the intellectual/developmental disabilities field. For questions, or to be notified of future Leadership Institutes, please send an email to info@nlcdd.org or visit our website at nlcdd.org

Join over 700 disability leaders as we examine how we develop strong leaders, support them in their work, and collaborate to reach our mutual goals. www.aucd.org/conference

is a proud supporter of Michigan Supporting and Including Brothers and Sisters (MI SIBS).

Best wishes to the Sibling Leadership Network and its 2015 Conference!

Our purpose is to honor and build connections through respect, reciprocity and relationships

Consultation • Facilitation • Education

5833 Community Drive • Brighton, MI 48116
Phone: 810.231.6364 • Fax: 810.231.6369
Email: communitydrive.inc@gmail.com
www.CommunityDrive.org
The Lee Specialty Clinic provides compassionate, interdisciplinary healthcare for people with mental and intellectual disabilities, as well as collaborative education and research programs unlike any teaching programs in the country.

Please visit our website at www.lee specialtyclinic.com for more information.

Quality Trust is an individual with disabilities (IQD) advocacy organization that educates, advocates, and empowers individuals with disabilities to live full and meaningful lives in the places and ways they choose. Quality Trust provides:

- One-to-one and system-wide legal advocacy
- Education and training in disability policy and practice
- Monitoring and consulting on quality of life issues
- Technical assistance and collaboration

TO LEARN MORE, CONTACT
Tina Campanella, Chief Executive Officer
202-448-1442 or tcampanella@dqualitytrust.org

www.JennyHatchJusticeProject.org
www.dqualitytrust.org

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collateral design /// packaging
design /// email + web design
general creative consultation

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