

ADULT SIBLING TRACK

The role of brother or sister changes dramatically as parents age. This track of workshops is designed to give adult siblings the tools they'll need to support their brother or sister. Packed with experts in financial planning, adult transition, employment and mental health, coupled with a few networking opportunities, adult sibs will leave feeling prepared, supported and empowered.



CONNECTIONS RECEPTION - THURSDAY, JUNE 27, 7:30 - 9:00 PM

Whether this is your first NDSC Convention or your third, attendees looking to network with other attendees who share similar experiences can come together at the **Connections Reception** to kick-off the convention weekend. Mingle among all attendees in the South Terrace and Pre-function area or join a focus group in one of the adjoining rooms to connect with your adult brothers and sisters to share your joys, concerns and strategies with peers whose life situations reflect your own.

PRE-CONFERENCE SESSION - FRIDAY, JUNE 28, 8:00 AM - 12:00 PM *(separate registration required)*

Pre-conference C: Building Bridges: A Holistic Approach to Transition



Andrew McCormick, MD, Director of Healthy Transitions Program, Down Syndrome Center of Western Pennsylvania - Children's Hospital of Pittsburgh, Pittsburgh, PA

Liz Mahar, Director, Family & Sibling Initiatives, The Arc of the United States, sister with DS, Washington, DC



Jacqueline Connell, JD, Attorney, ACHIEVA Family Trust, Pittsburgh, PA

Mary Hartley, Consultant, 446 Bridges, Pittsburgh, PA



Stephanie Smith Lee, Senior Policy Advisor, NDSC, Chair, Think College Accreditation Workgroup, daughter with DS, Charlotte, NC

Deb Hart, PhD, Director of Education and Transition, Institute for Community Inclusion, University of Massachusetts, Boston, MA

Becoming an adult is about making choices and making plans to move forward. The journey to adulthood is tough for any adolescent, but for teens with DS there are unique decisions that can be made in advance to encourage independence and success. Considering a holistic transition plan centered on the teenager's wants, wishes, and interests will support their long-term decision-making and support needs.

A multidisciplinary team of experts from the key areas of transition including decision-making, financial planning, employment, independent living, and healthcare will facilitate this workshop. Speakers will also discuss advocating for real opportunities in employment and postsecondary education during IEP meetings and meetings with vocational rehabilitation and support services. We hope this session will provide the audience with guidance on navigating the transition process and developing an individualized plan to adulthood for your adolescent with DS.



WORKSHOP OFFERINGS - FRIDAY, JUNE 28 - SUNDAY, JUNE 30

10 Focus on Life Planning and the Circles of Support

Hal Wright, CFP, MBA, Consultant, Special Needs Planning, daughter with DS, Centennial, CO

This workshop will provide practical guidance on how to develop a life plan for a child's future as an adult, teach life skills, design and implement the network of supports for independent living, establish circles of support, write letters of intent, and hold family meetings. The workshop will also address aging in the adult with DS, the possibility of early onset dementia, and options to address the concern including considerations for funding a trust.

12 The SELF Model: Sibling Empowerment, Liberty, and Fulfillment

Lara Liszka, OTD/S, Doctor of Occupational Therapy Student, Washington University in St. Louis, Program in Occupational Therapy, sister with DS, St. Louis, MO

Adult siblings often experience a role shift in becoming caregivers of their siblings with DS as their parents become no longer able to fulfill that role. Caregiving can create a physical and psychological strain on an individual, affecting other areas of their life due to the unpredictability and lack of control that comes with caring for someone. In this workshop, The SELF model: Sibling Empowerment, Liberty, and Fulfillment will be outlined in order to convey aspects of the sibling relationship that contribute to the complexity of the role shift. Additionally, this workshop will discuss how to seek out resources and supports in the local communities. Attendees will walk away with a personally-constructed approach to caregiving.

22 How to Recognize Regression in DS

Kristin Dalope, MD, MEd, Psychiatrist, Pediatric Behavioral Health Consultation and Liaison Services, Children's Hospital of Pittsburgh of UPMC, and Andrew McCormick, MD, Director of Healthy Transitions Program, Down Syndrome Center of Western Pennsylvania - Children's Hospital of Pittsburgh, Pittsburgh, PA

A pediatrician and a child and adolescent psychiatrist will discuss their experiences working with a teenager with DS who was identified to have regression. The workshop will focus on the approach to identify and help the teenager and his family overcome the challenges of regression.

27 Tips for Getting the Most out of Your NDSC Adult Sibling Toolkit

Tamara Pursley, Programs and Partnerships Director, NDSC, son with DS, Loganville, GA

This workshop will break down each section of NDSC's resource, the Adult Sibling Toolkit™, and will provide examples of how to begin the conversation with aging parents on planning for the future for their brother or sister with DS. Strategies will be shared for keeping everyone in a family working towards the same goal, as well as how to meaningfully include the sibling with DS in the process. Siblings will join the session to answer questions and share their experiences. Don't have an Adult Sibling Toolkit™? Don't worry, kits will be provided to each family at the workshop.

35 Promoting Strengths and Adaptive Resources in Persons With DS

Dennis McGuire, PhD, Senior Consultant, Global Down Syndrome Foundation, Denver, CO

This session will look at creative ways to adapt to challenges of concrete forms of thought and behavior. These challenges can greatly limit communication, flexibility, and adaptiveness to change; create problems generalizing

to new settings; and affect one's perception of time and humor. Discussion will include key behavioral characteristics such as 'grooves,' social sensitivity, visual memory, and visual cues and how they may be used creatively to compensate for the challenges of concrete thinking and behavior. Finally, how these characteristics may be used to solve a host of day-to-day problems and challenges which people may encounter in school and community settings will be addressed.

38 ABLÉ Accounts: A Down Payment on Financial Freedom

Miranda Kennedy, MPP, Director of the ABLÉ National Resource Center, National Disability Institute, Washington, DC, **Rachel Mast**, ABLÉ Account Owner and Self-Advocate, Olathe, KS

Achieving a Better Life Experience (ABLE) accounts are tax-advantaged savings accounts for individuals with disabilities and their families. Eligibility for public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test. Both ABLÉ accounts and special needs trusts (SNTs) are forms of protected asset accounts. Each allows for the accumulation of money, for the benefit of an individual with a disability, without jeopardizing key federally-based benefits. This presentation will compare ABLÉ accounts with two types of SNTs: First and Third Party Non-Pooled SNTs. Discussion will focus on when either a SNT or an ABLÉ account might be the preferred vehicle for savings/asset accumulation. Rachel Mast, a 19-year-old with DS who was the first ABLÉ account owner in Kansas, and her mother, Jawanda Mast, will be sharing their experience with ABLÉ account ownership and what it means for their financial planning now and in the future.

52 What Happens When the School Bus Stops Coming

Michele Leahy, MS, CPWIC, Disability Life Planner, CEO, Leahy Life Plan, Conshohocken, PA

Hours have been dedicated to evaluations, therapy sessions, and IEP meetings; however, the school services are coming to an end. What will life look like for the loved one with a disability in 10 or 20 years? What about after parent caregivers are gone? What government services and programs are available and how does one connect them to both the family's and the individual's goals? What benefits are people with disabilities entitled to versus what are they eligible for? What is the difference between SSI, SSDI, Medicaid, and Medicare? What about planning for how a loved one will live when family can no longer financially provide for them? Is it possible to find a loved one work without compromising their much-needed government benefits? These questions and more will be addressed in this session.

56 Ten Basic Financial Steps for Special Needs Caregivers

Kelly Piacenti, MA, Assistant Vice President, MassMutual SpecialCare, Somerset, NJ

This workshop will discuss ten basic steps to help caregivers get started in preparing for the financial future of their dependent with special needs. The single most important issue on one's mind, regardless of the age of the dependent, is what will happen to a dependent after one is gone. There are some needs that will always be present, and they must be carefully considered and planned for appropriately. This workshop addresses such critical issues as applying for government benefits such as Social Security and Medicaid, creating a special needs trust, the importance of a will, and considering a Letter of Intent. Taking these ten basic steps now can help ensure the type of care and quality of life for a loved one's well-being today and tomorrow.

67 The Soul Sisters Return

Michelle & Tanya Ponich, sisters, Edmonton, Alberta, Canada

Sisters by birth and soul sisters by choice, The Soul Sisters Return take participants through the journey of their lives together. Tanya, an advocate with DS, shares her views on life, her family, and what it is like being a 40-year-old woman with DS in today's world. Michelle, Tanya's older sister, speaks candidly about Tanya, their family's

journey, and the deep bond they share. They will speak of the challenges and adversity they have faced and how these experiences have made them into the women they are today. This session promises to inspire, give hope, and give suggestions on how to handle life's curve balls with love and a big dash of humor.

68 Your Story. Your Voice. You Make the Difference.

Heather Sachs, JD, Policy & Advocacy Director, NDSC, daughter with DS, Potomac, MD, and **Jawanda Barnett Mast, MS**, Disability Rights Advocate, daughter with DS, Olathe, KS, **Rachel Mast**, Self-Advocate and College Freshman, Olathe, KS

It is important for elected officials to understand why issues such as inclusive education, meaningful employment opportunities, comprehensive health care coverage that does not discriminate, and transportation and housing options for people with DS should be affordable and abundant. This workshop will give you the tools, resources, and training necessary to become an advocate for policy change. The NDSC Policy Team along with self-advocates like Rachel Mast will guide participants on the advocacy journey. The workshop will cover what grassroots advocacy entails, how to build relationships with elected officials, and how self-advocates can become meaningfully engaged in grassroots advocacy efforts. Individuals with DS, family members, and professionals in the DS community are all encouraged to use their voices to promote change. Voices are more powerful when they are united!

80 Movin' On Out

Carrie Bergeron, Sel-Advocate, Fairport, NY, and **Katie Bergeron Peglow, PT, MS**, COO - *Adaptivemall.com*, LLC, sister with DS, Dolgeville, NY

It is important to transition caregiver roles from one person to another when everything is good and everyone is doing well...not in the middle of a challenging time. For Carrie, the transition of caregiver roles from her parents to her sister, Katie, started with the move from her own apartment 45 minutes from her parents to one that was a mile from her sister. Katie is now on call for Carrie instead of mom and dad who are now 2.5 hours away. Come and learn about the challenges of transferring services from one county to another; finding safe and affordable housing; and identifying programs, classes and community opportunities to participate in.

82 Tools to Support a Future Plan

Liz Mahar, Director, Family & Sibling Initiatives, *The Arc of the United States*, sister with DS, Washington, DC

Planning for the future is important for all families. Experience shows that adults with intellectual disabilities make a better transition from the family home when a future plan is in place. Some families might feel that planning is not available to them because they don't have any money to leave to an adult son or daughter with intellectual disabilities or can't afford a lawyer or an estate planner. This is not true. There are many aspects of the planning process that aren't related to money. Staff from The Arc's Center for Future Planning will provide an overview of the resources available that support families to create a future plan.