

# 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, JULY 12, 7:00 - 9:00 PM

The **Connections Receptions** kick-offs the convention weekend with 13 different receptions that provide an opportunity to network with other attendees who share similar experiences. Receptions run simultaneously and will begin with a short ice-breaker activity to encourage audience participation for a meaningful networking experience. Attendees may mix and mingle in more than one reception. All receptions will have access to light snacks and a cash bar. The Adult Sibling Reception is designed especially for adult brothers and sisters to meet your peers and share your joys, concerns and strategies with others whose life situations reflect your own.

## PRE-CONFERENCE SESSIONS- FRIDAY, JULY 13, 8:00 AM - 12:00 PM

*(Separate registration required)*

### Extending the Continuum of Care: Aging Adults and Alzheimer's Disease



**Dennis McGuire, PhD, LCSW**, Senior Consultant,  
Global Down Syndrome Foundation

**Bryn Gelaro, LSW**, Director of Adult Initiatives and Special Projects,  
Global Down Syndrome Foundation

**Huntington Potter, PhD**, Professor of Neurology, Center Director,  
Alzheimer's Disease Program, Linda Crnic Institute for Down Syndrome

The average life expectancy for adults with Down syndrome has nearly tripled since the 1980s. To ensure people with Down syndrome are living both longer and healthier lives, we must educate families, caretakers, and providers and increase the scope of services available to support adults throughout the aging process. In this session you will learn about the behavioral and developmental processes typical of many older adults with Down syndrome, as well as common experiences and concerns identified by families and self-advocates. While every person's aging process is different, there are key considerations, including characteristics that can serve as coping mechanisms, a unique health spectrum, and a premature aging process, specific to this population that should inform the care and the creation of services for aging adults. In the second half of the presentation, we will review the most recent research discoveries related to Alzheimer's disease and Down syndrome. Find out how these discoveries are being translated into practice and what families and professionals need to know about Alzheimer's disease to support aging adults with Down syndrome.

## Creating the Best Possible Life for Your Child: Life Planning, Independence and Affordability



**Hal Wright, CFO**  
*Special Needs Planning Consultant*

People with Down syndrome have a right to a good life, an appropriate place in the community and to make decisions for themselves to the extent capable. Mr. Wright will describe how to create a life plan to enable the best possible life. He will cover how to plan for and transition to supported independence. He will also address the cost of independence and lifetime support so families can assess affordability. Parents with children of all ages are welcome because it is the children age 8 and under who may become the 4<sup>th</sup> generation of adults with DS, a generation who will live independently, find meaningful employment and perhaps escape from poverty. However, we must start now to teach them the life skills for self-management and independence to give them the opportunity.

### WORKSHOP OFFERINGS - FRIDAY, JULY 13 - SUNDAY, JULY 15



#### **11 After a Parent's Death: Transitioning the Care of an Individual With DS to the Next Generation**

**Sara Davis, PhD**, brother-in-law with DS, and **Michael Davis**, Self-Advocate, both from Eden Prairie, MN

In 2016, Michael, who has DS, came to live with his brother's family after the passing of his mother. The presenter will share the journey of transitioning Michael from his mother's care. It will include the legal and practical steps that were put into place prior to his mother's death that aided in a smooth transition, as well as the "misses" that required work and caused frustration. A checklist and templates will be provided to aid attendees in preparing for a smooth transition of their child's care to the next generation. Michael will talk about the aspects of his life that remained the same and many things that changed. The session will provide hope that the transition can go smoothly and the blending of an individual with DS into a sibling's family can be beautiful and fulfilling.



#### **26 Protecting Your Adult Child with Alternatives to Guardianship and Conservatorships**

**Tresi Moore Weeks, JD**, Founder and Attorney, Weeks Law Firm, Plano, TX

Until the end of your child's 17<sup>th</sup> year, you have legal control over all the major decisions in their life: housing, finances, school, health care, and even elements of everyday life. But, at 18 years old, your child gains legal control over all of these areas – and more. You might realize that your child isn't going to be ready to manage all of these things on their own at age 18. A child with a disability or special health-care needs might never be able to manage some or all of these things without your help. If this is true for your child's situation, you have choices that can help protect and support them. Making the right ones for your family is an emotional and complicated decision. This presentation will allow you to understand the best way to protect your adult child through alternatives to guardianship and conservatorships.



## 39 A Road Map to Hope – Creating a Circle of Support for Your Adult Sibling

**Chrissy Lewis, MS**, Full Life Process Consultant, and **Cynthia Witherspoon, MS**, Community Life Coordinator and Community Connector, both from Center For Independent Futures, Evanston, IL

The Full Life Process is an interactive, person-centered approach to developing a road map for your child's future learning in all areas of their life. Hopes and dreams, in partnership with beliefs and values, are at the heart of the process. We begin by using a skills inventory which determines the skills to develop and the support needed for a full, independent life. In addition, interviews and experiential observations are used to gather background information on your child. Our skills training offers support in learning advocacy, employment, transition, independent living, community engagement, and future planning. In this workshop you will receive a step-by-step overview of the skills inventory process and its implementation.



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

**Jolie Ganley, MEd**, Program Director, NDSC, brother with DS, Roswell, 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 your family working towards the same goal, as well as how to meaningfully include your sibling with DS in the process. Siblings will join the session to answer your 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.



## 62 Inclusive College Opportunities

**Christi Kasa, PhD**, Director, Office of Inclusive Services, **Julie Harmon**, NDSC Board Member, Inclusion Coordinator, Office of Inclusive Services, two sons with DS, **Mia Barone**, Student, and **Nick Harmon**, Student, all from University of Colorado Colorado Springs, Colorado Springs, CO

College inclusion is offering academic, social, and career opportunities for students with intellectual disabilities across the country, and in July 2016 Colorado legislators passed the Inclusive Higher Education Act. This session will share the legislative work needed to make this dream a reality and how supports and services can make college inclusion work. Learn firsthand from the students who are living the dream of attending college.



## 81 Tips for Transition: Guidelines for Adult Siblings and Caregivers

**Janice Nodvin**, Executive Director, Adult Disability Medical Home, Inc, son with DS, and **Andrea Videlefsky, MD**, Family Physician, Urban Family Practice Associates, both from Marietta, GA

Teens and adults with DS have special needs that are frequently not met within the traditional model of healthcare. As individuals with DS age more rapidly than the general population, they may encounter a variety of health, psychosocial, and intellectual conditions. At the same time, all individuals with disabilities have the goal of living in an inclusive community that is person-centered. Access to services and expertise in these areas is often limited. These frustrations are exacerbated when the caregiving role of a person with DS is transferred from parent to sibling. This workshop guides individuals, siblings, and other family caregivers regarding steps to developing comprehensive care and access to community-based services. The session will emphasize the strategies for navigating different medical and service providers serving adults with DS and related developmental disabilities.