

TRANSITION TRACK

We are all constantly transitioning throughout different stages of our lives. For individuals with DS the transition to adulthood is exciting as it signals independence and opportunity. For parents the process can be stressful and overwhelming when considering the medical, social emotional, education, employment, transportation and housing aspects. Taking the time to prepare and plan is the best way to manage the stress. Keep in mind that the process is a series of steps and not one single leap. Our hope is this track of workshop helps families and individuals with DS navigate this journey.



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 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

11 Parent Advocate: No Application or Experience Needed – You Have the Job

Nancy Murray, MS, President, The Arc of Greater Pittsburgh/ACHIEVA, son and daughter with DS, Pittsburgh, PA

This workshop will focus on advocacy – what it is, why it is important, and effective advocacy strategies. Past parent and family advocacy that resulted in major disability services, policies, and legislation will be discussed. In addition, current state and federal issues that are impacting children and adults with DS and their families and the vital role of parent advocates will be reviewed.

26 Understanding Special Needs Trusts and ABLÉ Accounts for Future Planning

Maria Smith, MEd, Director, Education and Outreach, ACHIEVA Family Trust, Pittsburgh, PA and **Jacquelyn Connell, Esq.**, ACHIEVA Family Trust Staff Attorney, Pittsburgh, PA

Individuals with disabilities and their families face significant challenges in planning for their futures. Concerns about the future are very real. Where will a family member live after parents are no longer alive? Who will look after their finances? When should future planning start? At ACHIEVA Family Trust, the core focus is working to plan for futures and enhance lives through special needs trusts. The presentation will focus on how special needs trusts and ABLÉ accounts can assist in that planning and still enable the individual with a disability to maintain essential government benefits such as medical assistance, Medicaid waivers, Supplemental Security Income (SSI), and Medicare.

42 Healthy Transitions: Pathway to Adulthood

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

The journey to adulthood is tough for any adolescent, and for kids with DS, there are unique challenges to overcoming the gaps in transition. These gaps often touch every aspect of their life and, therefore, require a holistic and longitudinal approach to building a path to adulthood. This workshop will be a “how to” on building a transition plan. Focus will be on the use of age-appropriate checklists as a guide through the transition process. Emphasis will include a basic understanding of the difficult decisions of transition such as power of attorney vs. guardianship, ABLÉ Act, and waivers. Focus will also include the importance of developing independence through the use of readiness assessment and goal development.

57 Employment for Individuals With DS: Developing Talents and Exploring Dreams

Michelle Durbin, MEd, Executive Director of Waiver services and Supported Employment, **Brianna Heitzman**, Employment Specialist, and **Zac Sappenfield**, Employment Specialist, all from Down Syndrome of Louisville, Louisville, KY

Everyone deserves the chance to develop their talents and explore their dreams. The purpose of this workshop is to show parents and guardians how individuals with DS can work in competitive employment, and that employment is possible and can be a meaningful part of their son or daughter's life. We will explore the value of work and how parents can help prepare their son or daughter for work. The most important thing is to raise expectations of what is possible for everyone.

72 Don't Put the Breaks on Before You Start: Transition to Adulthood for Parents

Mary Anderson Hartley, Consultant, 446 Bridges, Pittsburgh, PA

This session will discuss how the entire family can work as a team to bolster an individual's independence. It will focus on how to build your child's capacity as soon as possible, learn from mistakes, develop self-advocacy, manage challenging teenage issues that may arise, and understand the perfectly imperfect process of building a life that is driven by the person who is going to live it. Join a robust conversation on what it takes, what help is available, how the student can drive the ideas, and what natural public supports and community activities may be available. While each state operates differently, there are many common elements of transition that can support a family team in helping them make the experience as successful as possible.

86 Introduction to Inclusive Higher Education

Stephanie Smith Lee, Senior Policy Advisor, NDSC, Chair, Think College Accreditation Workgroup, daughter with DS, Oakton, VA, and **Debra Hart**, MS, Director, Think College, Institute for Community Inclusion, University of Massachusetts, Boston, MA, and **Beth Foraker**, Founder and Director of The National Catholic Board on Full Inclusion, Supervisor/Lecturer UC Davis School of Education Credential/Masters Programs, son with DS, Davis, CA, **Patrick Foraker**, Self-Advocate and student, George Mason University, Mason LIFE Program, Davis, CA

Learn about postsecondary education options and outcomes from national experts and hear from an experienced parent and student about their journey. Over 260 colleges and universities now offer postsecondary education opportunities for students with intellectual disabilities, including many students with DS. An overview will be provided of current college options and how to find them, model programs, federal financial aid, and other resources. Suggestions will be offered for finding the right "fit" and what questions to ask when considering an inclusive higher education program. The parent and student will share advice about preparing for college, finding the right fit, and success in college.