

Pre-Conference C



Building Bridges: A Holistic Approach to Transition



Andrew McCormick, MD, Transition Specialist, Assistant Professor Pediatrics, DS Center of Western PA, Pittsburgh, PA



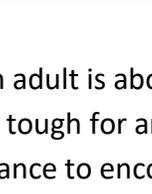
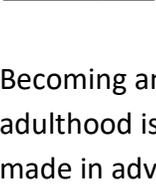
Liz Mahar, Director, Family & Sibling Initiatives, The Arc of the United States, sister with DS, Washington, DC

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.

Learning Objectives:

1. Participants will learn the differences between supported decision-making, power of attorney, and guardianship as they relate to their adolescent child with DS.
2. Participants will gain an understanding of SSI/SSDI, special needs trusts, and ABLE accounts.
3. Participants will learn the importance of advocacy during their IEP meetings and with vocational rehabilitation for transition to employment and independent living.
4. Participants will be introduced to postsecondary education options.
5. Participants will develop the skills and tools necessary to develop a healthcare transition team.

Outline:

- I. Introduction
 - A. What happens at 18 years of age
 - B. Purpose of transition
 - C. Transition pitfalls
 - D. Transition process

- II. Decision-making supports
 - A. What are my options?
 1. Supported decision-making
 2. Power of attorney
 3. Guardianship/Conservatorship
 - B. Q&A

- III. Financial transitions
 - A. Primer on SSI
 - B. Primer on special needs trusts
 - C. Primer on ABLE accounts
 - D. Q&A

- IV. Employment transitions
 - A. IEP, vocational rehabilitation, adult systems transition
 - B. Planning for the future checklist
 - C. Postsecondary education basics
 - D. Q&A

- V. Healthcare transitions
 - A. Transition team
 - B. Transition tools
 1. Policy statement
 2. Checklist
 3. Readiness assessment
 4. Portable medical summary

- VI. Caregiver panel
 - A. Intro
 - B. Transition experience
 - C. Largest challenges
 - D. Greatest successes

- VII. Closing remarks

About the Speakers:

Dr. Andrew McCormick is the Director of the Healthy Transitions Program at the Down Syndrome Center of Western PA. In this role, he has the pleasure of working with young adults and their families on the journey to a successful transition to adulthood.

Liz Mahar is The Arc's Director of Family & Sibling Initiatives. Previously, Liz spent five years as a consultant and Managing Supervisor for FleishmanHillard, managing stakeholder relations for government-funded public health campaigns on topics including binge drinking, drug abuse, and chronic diseases. She also brings social policy expertise from five years of working on capitol hill. Liz earned a Bachelor of Arts in psychology from the George Washington University in Washington, D.C. Liz is the sibling of a younger sister with DS.

Mary Anderson Hartley has developed a variety of solutions in employment, housing, and services in legislative/policy and real-world systems to increase inclusion for transition-age youth and adults. For the past six years, she has worked with individuals, families, businesses, and organizations through the 21 and Able initiative and #IWantToWork at United Way of Southwestern Pennsylvania, creating a bridge from youth to adult systems and private enterprise that did not previously exist. She is the parent of a 19-year-old son who is advocating through his own transition to adulthood in Pittsburgh.

Jaquelyn E. Connell, JD serves as Trust Attorney for ACHIEVA Family Trust. In her current role, she works with organizations, attorneys, families, and individuals with disabilities on reviewing and establishing special needs trusts. Prior to working at ACHIEVA Family Trust, she focused her practice on estate planning and estate administration. She has extensive experience in drafting and reviewing wills and powers of attorney, as well as advising clients on estate-planning techniques with regard to trusts, real estate, and long-term care. Jacquelyn is a member of the Allegheny County Bar Association and its Law and Disability section. She obtained a Bachelor of Arts summa cum laude and her Juris Doctor from Duquesne University.

Stephanie Smith Lee has over thirty years of experience in public policy including serving in senior Congressional staff positions and as a nationally-recognized disability expert. Since her daughter, Laura, was born with DS in 1982, she has led many successful disability advocacy efforts at the local, state, and federal levels and served as Vice President of the National Down Syndrome Congress in the mid-1990s. As the Director of the Office of Special Education Programs (OSEP) in the US Department of Education, Ms. Lee was responsible for the implementation of IDEA, the federal special education law. As Senior Policy Advisor for the National Down Syndrome Society's Policy Center from 2005 through 2012, she developed and trained an effective grassroots campaign, advocated with Congress, and directed a postsecondary education project. Ms. Lee is directly involved in developing inclusive postsecondary projects for students with ID in various states and led a successful effort to obtain federal financial aid and model demonstration programs for these students. As Senior Policy Advisor for NDSC, she chairs the Think College accreditation workgroup that developed model accreditation standards for these programs and chairs the committee to promote postsecondary education for students with intellectual disabilities.

Deb Hart is Director of Education and Transition for the Institute for Community Inclusion at the University of Massachusetts, Boston. She has over 30 years of experience working with students with disabilities, their families, and professionals to support youth in becoming valued members of their community via participation in inclusive K-12 education, higher education, and competitive employment. Debra is also the co-author of a book *Think College! Postsecondary Education Options for Students with Intellectual Disabilities* and numerous other professional and peer-reviewed publications.