



2025 NDSC CONVENTION CELEBRATING ALL

DEEP DIVES

Deep-dive sessions are offered in addition to our regular workshop cycles as an opportunity to spend 3 hours with an expert. Because not all General Conference attendees are interested in these intense sessions, an additional charge (\$75) is applied to only the individuals interested in participating in Deep-Dive sessions. Only choose one Deep Dive per attendee.

**FRIDAY, JULY 25
8:30 AM - 11:30 AM**

Aging and Down Syndrome Deep Dive: Using existing tools and NDSS resources to prepare for a healthy future

Dr. Daniel Combs, MD, Assistant Professor, Pediatrics and Medicine, University of Arizona

Dr. Michael Rafii, MD, PhD, Medical Director, Alzheimer's Therapeutic Research Institute (ATRI) and Professor of Clinical Neurology at the Keck School of Medicine

Dana Scullo, MOT, OTR/L, Manager of Health Programs, National Down Syndrome Society

Medical

This expert panel (speakers to be added) presentation will address the potential needs of individuals with Down syndrome as they age including Down Syndrome Regression Disorder, mental health, Alzheimer's disease, and sleep quality which affect overall quality of life. Our panelists will identify key factors for healthy aging through the provision of up-to-date research and information for individuals, families, and caregivers. NDSS will present resources and useful tools to help you build a healthy future for your loved one with Down syndrome.

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

Hal Wright, CFP (Retired)

Financial

The speaker passionately believes that all people with Down syndrome have a right to an appropriate place in the community and the right to make decisions affecting their own lives to the extent capable. He believes that living independently is possible for many of our children with adequate planning, supports, and financial resources.

This "Deep Dive" covers:

- 1) Life planning for an adult with Down syndrome, including developing a life plan, establishing a circle of support, writing a letter of intent, and estate planning, including funding a special needs trust
- 2) "A Home of Her Own", living in supported independence
- 3) The Angel Herrera Case Study

The Case Study presents a summary life plan for a twenty-one year old woman with Down syndrome, the estimated cost of her lifetime support and funding for her special needs trust. The purpose is to give parents a realistic picture of what a comprehensive life plan might look like.



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The Gifts and Challenges Exchange, for and by Families of Teens and Adults

Dr. Dennis McGuire, LCSW, PhD, (private practice)

Adult Life

Following a brief introduction of the 7 key challenges reported by families at the Adult Down Syndrome Center, including self talk, the 'groove,' social emotional issues, expressive language limitations, the need for independence, concrete thought and behavior, participants will be invited to share:

- Challenges from their recent and past experiences
 - Solutions to challenges, including creative and innovative ideas and strategies
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Let's Raise Expectations For Speech Clarity & Verbal Language

Sarah Bookout, CCC-SLPD, Speech-Language Pathologist, GraySpeak Therapy

Jennifer Gray, MS, CCC-SLP, Speech-Language Pathologist, Grays Peak Speech Services, LLC

Communication

This session will outline how speech therapy should assume ability and expect competence by planning for future independence. It can be argued that speech and language therapy is the most important part of intervention services for children with Down syndrome if we wish to promote their cognitive (mental) and social development. Speech and language therapy must, therefore, prepare children with Down syndrome to achieve and maintain verbal language abilities throughout the lifespan. Especially considering 97% of those with Down syndrome will choose to use speech to communicate, even in the absence of success. Challenges with speech clarity, language development, and social communication due to structural differences and intellectual development should be addressed in infancy and continue through adulthood. Every person with Down syndrome has the ability to learn, speak, prepare, plan, and achieve goals when practiced with high frequency and intensity.

Supporting Mental Health: Practical Strategies for Parents and Caregivers of People with Down Syndrome

Dr. Ruth Brown, PhD, Clinical Psychologist, Assistant Professor, Virginia Commonwealth University

Dr. Jill Fodstad, Ph.D., BCBA-D, Associate Professor of Clinical Psychiatry, Indiana University School of Medicine

Dr. Emily Meudt, MD, Medical Director, Down Syndrome and Developmental Regression Clinic at Indiana University Health

Behavior

This deep dive session provided by a panel of mental health providers in the fields of psychology and psychiatry offers practical, evidence-informed strategies to help parents and caregivers foster mental health and emotional wellness in individuals with Down syndrome, across all stages of life. Participants will learn how to identify early signs of emotional or behavioral changes and understand the critical connection between physical health and emotional well-being. A brief discussion on when to reach out to a licensed mental health professional for diagnostic evaluation or mental health services and what to expect from these professionals will occur. The session will provide actionable advice on using structured, visual-based approaches to support emotional regulation. Attendees will also explore ways to encourage social connectedness, physical activity, and effective communication, ensuring that individuals with Down syndrome feel empowered and supported in their emotional growth.



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Estrategias para Educación Sexual y Afectividad: DEEP DIVE

Macarena Lizama

Sexuality/Relationships

Taller teórico práctico de estrategias para enseñar educación sexual y afectiva a personas con discapacidad cognitiva. El taller está basado en el libro sobre educación sexual y afectividad para personas con discapacidad cognitiva, que contempla tanto teoría como actividades prácticas, secciones de aprendizaje en podcast y lectura autónoma en formato de lectura fácil. Se enfoca en poder enseñar desde la infancia y siempre, abordando temas de autorreconocimiento e identidad, autocuidado, desarrollo puberal, ciclo menstrual, masturbación, relaciones de pareja, relaciones sexuales, entre otras.