



2020 WORKSHOP DIRECTORY

(As of June 5, subject to change)

Week One

All times shown in Eastern

An NDSC Housecall – A Talk with the Docs

May 11, 2020 - 3:30 PM

Doctors Kishore Vellody, Nicole Baumer and Peter Bulova will candidly answer your Top 10 Questions. These docs are all experts in their fields and members of the Down Syndrome Medical Interest Group (DS-MIG).

Promoting Strengths and Adaptive Resources in Persons with Down Syndrome

May 13, 2020 - 5 PM

Dennis McGuire, Ph.D., Senior Consultant, Global Down Syndrome Foundation, Denver, CO

There are creative ways to help people with Down syndrome adapt to challenges involving the use of concrete forms of thought and behavior. These challenges can greatly limit communication, flexibility and adaptive-ness to change, create problems generalizing to new settings, as well as to affect one's perception of time and of humor. We will reiterate key behavioral characteristics such as 'grooves,' social sensitivity, visual memory, and visual cues and discuss how to use them to compensate for the challenges of concrete thinking and behavior. We will also discuss how these characteristics may be used to solve a host of other problems and concerns.

Inclusion Is for the Included: Breaking Barriers with Self-Determination and Advocacy

May 14, 2020 - 2 PM

LaTaasha Byrd, President, Countdown to K, Inc., daughter with DS, Orlando, FL

The session speaks to the social stigmas and cultural imbalances minority families face when caring for individuals with Down syndrome and other developmental disabilities. It highlights differences in cultural norms and practices and shares personal and practical insight in steps families can take to break the barriers of inclusion and access to resources, even within the family unit. Positive inclusive efforts, as shown during the presentation, are poignant reminders that these individuals are people first and the disability is only a small factor in their unique abilities. 'Inclusion' illustrates inclusive efforts from the aspect of a single minority special needs family successfully navigating the course of inclusion from family, the community, and the national stage.

Early Intervention Strategies and Supports

May 19, 2020 - 1 PM

Stacy Taylor, MA, BCBA, Owner, Advance Behavior & Learning, daughter with DS, Maitland, FL

Families who have infants and toddlers with a disability are often confused about how to best promote early learning and development at home. We know that this is a critical period of time, but what can you really do with a baby? Well...LOTS! Come and find out strategies that early interventionists use so you can help get your little one off to a great start.

Ten Basic Financial Steps for Special Needs Caregivers

May 20, 2020 - 3 PM

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.

Ditching the Diapers: How to Move Forward with Toileting

May 21, 2020 - 4 PM

Terry Katz, PhD, Psychologist, Children's Hospital Colorado, University of Colorado School of Medicine, Aurora, CO

This presentation will cover issues related to toileting. We'll discuss the challenges involved in toilet training children with special needs, discuss ways to teach this important skill, and review useful and practical strategies.

I Want a Boyfriend (or Girlfriend)! Supporting Healthy Dating Relationships

May 26, 2020 - 1 PM

Terri Couwenhoven, M.S., AASECT-certified sexuality educator, Clinic Coordinator for the Down Syndrome Clinic at Children's Hospital of Wisconsin, daughter with DS, Port Washington, WI

The need for intimacy and meaningful connections with others is part of the human condition. People with Down syndrome and other intellectual disabilities have similar needs for intimacy, but often encounter a unique set of barriers as they enter the world of dating. In this workshop, common issues and obstacles experienced by individuals with intellectual disabilities will be explored, helpful roles for parents/support providers, and strategies for supporting individuals interested in dating.

The NDSC and Me

May 26, 2020 - 3 PM

Kate Dougherty, NDSC Board VP, President & Founder of Down Country, son with DS, Taylor, MO, and ***Shauntel Neal-Howe***, NDSC Board VP, daughter with DS, Smyrna, GA

This session aims to help you understand who the NDSC is and what it can do for families and communities (especially those living in rural and/or underserved areas). Told through the testimonials of Kate & Shauntel, they will share their journeys and stories of: what the NDSC does, how that has personally affected their families & communities, and how it can continue to help yours too!

Tips and Tools for Online Learning

May 28, 2020 - 5 PM

Sean Smith, PhD, NDSC Board Member, Professor, Department of Special Education, University of Kansas, son with DS, Lawrence, KS

This session will focus on succeeding in online and distance learning. Participants will learn about ways both parents and educators can collaborate to support the needs of our learners, design for the new normal, determine student success, and extend ways to engage our students. Digital tools, strategies, and effective practices will be discussed to assist planning for the fall fully online or blended learning experience.

Week Four

THROWING OUT THE BOX

June 2nd, 2020 - 2 PM

Kate Dougherty, NDSC Board VP, President & Founder of Down Country, son with DS, Taylor, MO

Goal of this workshop is THROW OUT THE BOX – presented from an application standpoint. The definition of stupidity is doing the same thing and expecting different results. This presentation is geared towards no longer striving to think outside the box, but getting rid of the box all together. Multiple apps, philosophies, strategies and programs from both a high tech and low tech perspective and educational and life access point will be shared. Presented from a real life application standpoint and easy to use.

Feeding Challenges and Nutrition Opportunities for Children and Adults with DS-ASD

June 3, 2020 - 2 PM

***Dominica Nichols, PhD, RD, LDN**, Clinical Dietitian/Nutritionist, MassGeneral Hospital Down Syndrome Program, Boston, MA*

This workshop will review some of the feeding challenges and nutritional opportunities for children and adults with a dual diagnosis of Down syndrome and Autism. While many of the nutritional needs are the same, there are specific factors that may create barriers to access age-appropriate nutrition. We will discuss these challenges and specific strategies that can be utilized with support from family members, caregivers, school staff and specialty therapists when available.

Maximizing Language Skills from Birth to Preschool

June 3, 2020 - 4 PM

***Libby Kumin, MD**, Professor Emeritus of Speech-Language Pathology/Audiology at Loyola University, Baltimore, MD*

The session will focus on helping children with DS develop communication and language skills from birth to kindergarten. What are the differences between communication, language, and speech? What prepares your child to speak? What can you do at home with your child before the first word? How does your child progress from sounds to words to conversation? Dr. Kumin will describe and demonstrate examples of activities you can do at home to promote the development of communication. Transitional systems to promote communication and language before your child begins to speak and activities to expand speech once your child begins to speak will be addressed. She will also address the role of play and how it can be used to stimulate language. Dr. Kumin will also discuss effective techniques for working with IFSP teams, IEP teams, and speech language pathologists in preschool and early elementary school, clinical, and private practice settings.

Week Five

Common Questions (and Answers!) about Health Conditions in Adolescents and Adults with Down Syndrome

June 9, 2020 - 2 PM

***Brian Chicoine, MD**, Medical Director, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL*

What are the most common health conditions experienced by adolescents and adults with Down syndrome? In this presentation, Brian Chicoine, MD, will discuss diagnosis and treatment of common health conditions in adolescents and adults with Down syndrome. He will also share information about free resources that can be used by people with Down syndrome, their families and caregivers, and their health care and service providers to promote health and wellness. Dr. Chicoine will discuss how these resources apply not only to the clinical setting but also to residential, vocational, and other community settings.

Have Questions? Ask the Doctor (0-12)

June 10, 2020 - 2 PM

***Kishore Vellody, MD**, President, NDSC Board of Directors, Medical Director, Associate Professor of Pediatrics, Down Syndrome Center of Western Pennsylvania, brother with DS, Pittsburgh, PA*

For caregivers of a child with DS, it can be challenging to find accurate and up to date information on the internet or sometimes even from their healthcare providers. During this workshop, NDSC President Dr. Vellody will share his knowledge not only from his decade-long leadership of the Down Syndrome Center of Western Pennsylvania but also from his life-long interaction with his brother who has Down syndrome. This engaging and interactive workshop aims to provide easily understood answers to a wide variety of anonymously submitted audience questions.

Stop, Squeeze, Breathe – Sensory-Based Calming Strategies for All

June 10, 2020 - 5 PM

***Jamie McGrew, MOTR/L**, Lead Occupational Therapist, and **Sarah Mann, PT, DPT, MBA**, Doctor of Physical Therapy, both from Mann Method Physical Therapy and Fitness, PLLC, Arvada, CO*

This workshop provides self-advocates, parents, teachers, therapists, and caregivers with the opportunity to step back from the intensity of the moment and challenging day-to-day behavior patterns. OT and sensory specialist, Jamie McGrew, will lead participants through an understanding of the underlying physical sensory-motor elements behind behavior. Even more importantly, participants in this workshop will leave with an understanding and practice of Jamie's five favorite calming strategies not only for self-advocates, but for caregivers as well. These activities help individuals identify behavioral triggers, reset in the moment, and implement coping strategies to choose more functional and productive behaviors.

Introduction to Inclusive Higher Education

June 11, 2020 - 2 PM

***Stephanie Smith Lee**, Senior Policy Advisor, NDSC, Chair, Think College Accreditation Workgroup, daughter with DS, Charlotte, NC, **Debra Hart**, MS, Director, Think College, Institute for Community Inclusion, University of Massachusetts, Boston, MA,*

Higher education opportunities for students with intellectual disabilities (ID) have greatly expanded over the past 15 years as a result of advocacy and improvements to the Higher Education Act. In this interactive session, experts will provide an "intro" to inclusive higher education, sharing information about the over 280 college programs for students with ID, how to find the right fit, how to apply for financial aid, and tips for preparing for college while in K-12. Think College staff will describe how to use their database of college programs and the positive outcomes from the evaluation of federally-funded model programs. Helpful resources will be provided and the workshop will include time for discussion and questions and answers.

Beyond CPAP: The New Era of Sleep Apnea Treatment

June 11, 2020 - 4 PM

***Raj Dedhia MD MSCR**, Director, CPAP Alternatives Clinic & Division of Sleep Surgery University of Pennsylvania and **Nikhila Raol, MD MPH**, Emory University/Children's Healthcare of Atlanta*

Obstructive sleep apnea affects more than 1 out of 3 individuals with Down Syndrome. Roughly 50% of Down syndrome patients are not able to tolerate the CPAP machine. In the last 5 years, new procedures for sleep apnea have become available. Hypoglossal nerve stimulation (Inspire) is now FDA approved in the United States. Two of the nation's physician leaders in sleep apnea care will provide background, data and personal experience about this treatment and other CPAP alternatives for persons with Down syndrome.

Week Six

What's Happening in Washington DC and What You Can Do

June 16, 2020 - 2 PM

***Heather Sachs, JD**, Policy & Advocacy Director, NDSC, daughter with DS, Potomac, MD, **Stephanie Smith Lee**, Senior Policy Advisor, NDSC, daughter with DS, Charlotte, NC, and **Ricki Sabia, JD**, Senior Education Policy Advisor, NDSC, son with DS, Silver Spring, MD*

NDSC's Policy & Advocacy Team will discuss the status of key laws and policies, changes that are being proposed, and how these proposals would affect the future of people with DS. This will include administration action as well as the latest developments in education laws and policies, prospects for improving employment outcomes for individuals with disabilities, and health care policy updates. We will also discuss what families and advocates can do to be vigilant, organized, and act with a unified voice to protect and advance rights, services, and opportunities for individuals with DS and other disabilities.

Desensitization to Use of Medical Equipment and Procedure Related Distress

June 16, 2020 - 4 PM

***Lina Patel, MD**, Director of Psychology, Anna and John J. Sie Center for Down Syndrome at Children's Hospital, Aurora, CO*

This presentation will focus on identifying factors impacting adherence to the use of medical equipment and participation in medical procedures. A clear plan will be provided for steps towards desensitization. This will include creation of a schedule for practicing, identifying motivators, and troubleshooting of challenging behaviors. Strategies to help tolerate medical appointments and procedures (earwax clean out, shots, blood draws etc.) as well as other stressful events like dental visits and haircuts will be shared. Participants will learn how to identify why a child may be struggling in these situations and then learn strategies to manage behaviors.

Home Is Where You Hang Your Hat

June 17, 2020 - 7 PM

Denise Gehringer, Executive Director, Sheltering Tree

This forum will offer discussion about the variety of living choices for adults with Down syndrome that includes options for all levels of support needs. Additionally, information related to adult living will be provided.

An Important New Resource: Global Medical Care Guidelines for Adults with Down syndrome

June 18, 2020 - 1 PM

Michelle Sie Whitten, President & CEO, Global Down Syndrome Foundation, daughter with DS, Denver, CO, and Bryn Gelaro, LSW, Director Adult Initiatives & Special Projects, Global Down Syndrome Foundation, Denver CO, Brian Chicoine, MD, Medical Director, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL

Global Down Syndrome Foundation (Global) is currently working to update and publish the “Global Medical Care Guidelines for Adults with Down Syndrome.” The Global Guidelines provide the first evidence-based, updated recommendations to families, caregivers, individuals with Down syndrome (DS), & medical providers in the US. Participants will be provided an overview of the topics & key recommendations and an overview of the patient toolkit that helps families understand & use the Global Guidelines. The guideline creation process, focus group input, how/why the Global Guidelines may differ from previous recommendations, & the roadmap to future research needed will also be covered.

All about D.A.D.S. Dads Appreciating Down Syndrome

June 18, 2020 - 6 PM

Stephen Simpson, Director, D.A.D.S. National, son with DS, Indianapolis, IN

The DADS mission is to assist and support through fellowship and action the fathers and families of individuals with Down syndrome. This is a presentation and workshop on how we started the organization, how we endeavor to fulfill this mission and our current status. There will be an interactive presentation on DADS with the intent of turning the presentation into a DADS Meeting. While this is targeted to fathers and other family members Ds organization leadership members are also welcome to attend to learn about the organizational aspects of DADS.