

2019 WORKSHOP DIRECTORY

(As of March 21, subject to change)

FRIDAY, JUNE 28, 1:30 -3:30 PM

1 Reading Intervention for Children and Adolescents With DS



Christopher Lemons, PhD, Assistant Professor of Special Education, Peabody College of Vanderbilt University, Nashville, TN

Learning to read is an important skill that supports future educational outcomes, employment, and independence. The goal of this session is to provide a model of literacy for individuals with DS, to summarize recent research that has enhanced our understanding of effective methods to teach reading skills, and to provide strategies for supporting literacy development in children and adolescents with DS. Time will be provided for questions and discussion.

2 How to Address Messy Eating and Feeding Safety Through Specific Oral-Motor and Self-Monitoring Skills



Jennifer Gray, MS, CCC-SLP, Owner and Speech-Language Pathologist, Grays Peak Speech Services, LLC, Broomfield, CO

People with DS experience difficulties throughout the lifespan that affect feeding, eating, and drinking. Great strides have been made to improve health, safety, and independence; however, there remain some concerns that impact quality of life that aren't always recognized. Some of these issues include respiratory health, open-mouth breathing, sleep hygiene, self-awareness, seated-body positioning, and flavor and pain registration. This presentation will discuss these common issues, how they can be addressed within the overall framework of health and independence, and strategies for managing these concerns using video demonstrations and sample materials.



3 **Top 5 Issues and Concerns During Puberty: A Parent's Guide to Supporting Pre-Adolescent Females With DS**

Terri Couwenhoven, MS, CSE, Certified Sex Educator, TC Services, daughter with DS, Port Washington, WI

Families often experience anxiety when their daughters with DS begin exhibiting the physical and emotional changes that accompany puberty. In this workshop, parents will learn about the most common issues and concerns of parents of females with DS and practical ways to address them. Visual tools, fun learning activities, and useful teaching resources specific to females with intellectual disabilities will be shared.



4 **From Home to the Classroom: Communication Challenges for School-Age Children With DS**

Elizabeth Gilbert, MA, CCC-SLP, Director, Therapy Works LLC, sister with DS, Venetia, PA

School-age children with DS have both communication strengths as well as areas of need. Speech-Language Pathologist, Betsy Gilbert, details the different models of therapy and gives families and professionals practical strategies for communication success in the home, community, and classroom.



5 **Self-Advocacy in Your Community & for Your Employment**

John Seely, Executive Director, Empowering Lives Foundation, son with DS, Altoona, PA, and Michael Gamel-McCormick, Senior Policy Director for Sen Robert Casey D-PA, Washington, DC

This workshop will provide the basic skills necessary to advocate in your community, at work, and within our government to influence policy. Learn how to create a One Page Profile and hear from professional advocates and Senator Casey's lead disability policy director about ways to get involved.



6 **Friendship Toolkit**

Jane Stadnik, Parent Advisor, and Kelly King, Family to Family Health Information Coordinator, both from PEAL Center, Pittsburgh, PA

PEAL has developed a new resource, "Friendships: Building a Good Life -- Strategies for Families of Children with Disabilities and their Peers, Communities, and Schools." This is an interactive session to help participants understand how they can facilitate natural opportunities for building friendships and make a difference in someone's life. Participants will receive a copy of the Friendship Toolkit. The workshop will review the design and organization of the booklet as well as discuss three guiding principles: Everyone has a role to play in the development of friendships, friendships are important to ALL, and everyone benefits when friendship development for kids with disabilities is supported.

7 The Down Syndrome Diet: Changing the 'Course' Through Nutrition



Jennifer Kimes, PsyD, Executive Director of Education and Clinical Services, Down Syndrome of Louisville, daughter with DS, Louisville, KY



Discover how to eliminate or reduce the symptomatology of many of the health and developmental issues impacting children and adults with DS including autism, ADD, diabetes, hypothyroidism, and Alzheimer's dementia. A literature review implicating the high sugar and carbohydrate diet with many of the gastrointestinal, neurological, endocrine, and immune system dysfunctions associated with DS will be presented. A synthesis of recent research regarding dietary interventions will be discussed and recommendations from health care providers will be reviewed to see how to change the course of the declining outlook for healthcare epidemics affecting individuals with DS.

8 LuMind RDS - Leading the Way in Down Syndrome (DS) Research: Why We Should Be Excited About the Future



James Hendrix, PhD, Chief Scientific Officer, and **Hampus Hillerstrom**, President and CEO, both from LuMind RDS Foundation, Burlington, MA

A general perception shared by families, doctors, the general public, and the pharmaceutical industry is that finding therapies to improve independence or health in people with DS is too complex; however, major advances in education, early intervention, acceptance, and inclusion for people with DS have been made, while pharma has largely stayed away. Now there is a new generation of adults with DS who are living longer, but are facing unprecedented challenges with dementia and other conditions that are not fully understood. LuMind RDS has responded by building the \$3 million DS-CTN (DS Clinical Trials Network) with 11 leading clinical research centers nationwide. The DS-CTN is starting with a group of adults to study their risk factors for progressing to Alzheimer's disease.

9 Foot Problems Associated With People With DS



Lorri Riley, DPM, Podiatrist, nephew with DS, Spearfish, SD

Over 95% of people with DS have flat feet. Dr. Riley will talk about bunions, ankle instability, and knee and hip problems associated with DS. Other topics addressed will be nail and skin issues, braces, insoles, and surgical options.

10 Focus on Life Planning and the Circles of Support



Hal Wright, CFP, MBA, Consultant, Special Needs Planning, daughter with DS, Centennial, CO



This workshop will provide practical guidance on how to develop a life plan for a child's future as an adult, teach life skills, design and implement the network of supports for independent living, establish circles of support, write letters of intent, and hold family meetings. The workshop will also address aging

in the adult with DS, the possibility of early onset dementia, and options to address the concern including considerations for funding a trust.

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.

12 The SELF Model: Sibling Empowerment, Liberty, and Fulfillment



Lara Liszka, OTD/S, Doctor of Occupational Therapy Student, Washington University in St. Louis, Program in Occupational Therapy, sister with DS, St. Louis, MO



Adult siblings often experience a role shift in becoming caregivers of their siblings with DS as their parents become no longer able to fulfill that role. Caregiving can create a physical and psychological strain on an individual, affecting other areas of their life due to the unpredictability and lack of control that comes with caring for someone. In this workshop, The SELF model: Sibling Empowerment, Liberty, and Fulfillment will be outlined in order to convey aspects of the sibling relationship that contribute to the complexity of the role shift. Additionally, this workshop will discuss how to seek out resources and supports in the local communities. Attendees will walk away with a personally-constructed approach to caregiving.

13 DS-ASD 101: Understanding the BASICS of Co-Occurring DS and Autism Spectrum Disorder



Charlotte Gray, Executive Director, son with DS-ASD, and **Jeanne Doherty**, Board President, daughter with DS-ASD, both from the Down Syndrome-Autism Connection and living in Massachusetts



DS and autism can be challenging disabilities separately; however, when combined the challenges can be quite complex and oftentimes are misunderstood by the family members and professionals in the individual's life. This workshop will take a look at what is known about DS-ASD, discuss commonalities in family experiences, explore basic behavioral red flags, discuss treatment recommendations, and share the importance of building a support network and care team through the lifespan.

14 **8 principios claves en el desarrollo integral del niño con síndrome de Down: herramientas prácticas para padres y educadores**

María Ignacia Larrain Vacarezza, Psicóloga, Asesora, Fundación Chilena para el síndrome de Down Complementa

En este taller se reflexionará en torno a 8 principios que, a lo largo de la experiencia de 27 años trabajando con niños y jóvenes con síndrome de Down y sus familias, han mostrado ser fundamentales para que ellos logren desarrollar al máximo su potencial en las diversas dimensiones de la vida. Se trata de promover un desarrollo armónico, donde los aspectos cognitivos, sensoriales y motores se articulen e integren con un sano desarrollo social y emocional, pues ésta es la forma a través de la que el niño llegará a ser una persona autónoma, que se acepte, se valore y que, desde sus propias posibilidades, pueda contribuir a su familia y a su comunidad. Estos 8 principios son verdaderas guías orientadoras que permiten, en diversos momentos de la vida, reflexionar y revisar la forma y el sentido con el que estamos conduciendo el proceso de formación de nuestros hijos. En base a ellos podremos, posteriormente, revisar las pautas educativas y estrategias concretas que nos permiten avanzar en cada una de estas dimensiones. Para ello se presentará una colección de cuadernillos elaborados multidisciplinariamente por la Fundación Complementa, en la que se sistematizan las principales estrategias que podemos utilizar para potenciar cada uno de los ámbitos del desarrollo y así promover una buena calidad de vida.

SATURDAY, JUNE 29, 9:30 -11:00 AM

16 **Foundations for Successful Communication**



Jennifer Bekins, MS, CCC-SLP, DDBP Speech Pathology Coordinator, Cincinnati Children's Hospital, Cincinnati, OH

Families have many questions about speech and language in young children with DS, especially “When will my child talk?” Participants in this interactive session will get an overview of communication development in children with DS from birth to early childhood. Discussion will include speech-language milestones, treatment techniques, and alternatives to spoken communication. Family-friendly tips, tricks, and tools will be shared throughout the workshop.

17 **Making a Splash With Aquatic Therapy: An OT/PT Group Approach**



Helen Milligan, MPT, Physical Therapist, Trisomy 21 Program, son with DS, Philadelphia, PA, and Michelle Hagenbaugh, MS, OTR/L, Occupational Therapist, both from Children's Hospital of Philadelphia, PA

The Trisomy 21 aquatic therapy program at the Children’s Hospital of Philadelphia has been providing aquatic therapy groups for children from 10 months to 6 years for the past 8 years. This interactive presentation will highlight the fun activities and basic routines used during the groups. Parents will learn how they can easily carry over the same activities in their personal or community pool. Presenters will

also illustrate how skills facilitated and gained in the pool can be translated to functional routines and activities on land. Pictures and videos will be used to demonstrate all concepts. Helen will share how her son Aidan and others with DS can benefit from using the pool from infancy through adulthood as a fun way to exercise, gain new functional skills, be included, and promote independence.

18 The ABCs of Effective Reading Instruction



Dana L. Halle, JD, NDSC Board Member, Executive Director, Down Syndrome Foundation of Orange County, son with DS, Orange County, CA

This session will provide participants with evidence-based strategies, resources, and activities for effective literacy instruction for learners with DS. Intended for those working with new readers of any age, topics will include developing vocabulary, acquiring sight words, building sentences, and introducing sounds and letters. Activities will be illustrated with pictures and video examples from students in Down Syndrome Foundation’s The Learning Program™ and After School Academy™.

19 Developing a Strong IEP



Diane Perry, Parent Advisor, son with DS, and **Ana Pacheco**, Parent Advisor, both from The PEAL Center, Philadelphia, PA

This session will provide an overview of the key principles of IDEA and will highlight the importance of families being “informed decision-makers.” Each section of the IEP will be reviewed, highlighting the contributions that family members and youth can make. Ways to identify the student’s strengths and talents that can be built upon in the IEP process will be discussed. Participants will receive a copy of Pennsylvania’s “annotated IEP” that contains helpful information about what should be included in each section of the IEP.

20 Practical and Effective Use of Technology – Throwing Out the Box



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

The goal of this workshop is to expose attendees to technology applications that are easy to use, practical and impactful in addressing education and development needs of children with DS. Put on your seatbelt for this energized and practical demonstration and discussion of high and low technology that can make a difference for your child’s development.

21 The Next Phase of Support and Planning: Adult and Aging Support



Christy Gregg, CTRS, Adult Matters Coordinator, Down Syndrome Association of Greater Cincinnati, brother with DS, Norwood, OH

“Planning is bringing the future into the present so that you can do something about it now.” (Alan Lakein) Join this session to learn about planning for the future and supporting adults as they age. The life expectancy for an adult with DS is very different than it was in the 80’s. With these new changes in life expectancy, there is not a paved road of support already in place. This next phase of support is still being built. The aging process will be briefly discussed and then a dive into how to plan and create a vision for the future. Tools and resources to assist in this planning will be reviewed.

22 How to Recognize Regression in DS



Kristin Dalope, MD, MEd, Psychiatrist, Pediatric Behavioral Health Consultation and Liaison Services, Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA and **Andrew McCormick, MD**, Director of Healthy Transitions Program, Down Syndrome Center of Western Pennsylvania - Children's Hospital of Pittsburgh, Pittsburgh, PA

A pediatrician and a child and adolescent psychiatrist will discuss their experiences working with a teenager with DS who was identified to have regression. The workshop will focus on the approach to identify and help the teenager and his family overcome the challenges of regression.

23 What’s Happening in Washington DC and What You Can Do



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.

24 Behavior & DS: The Respond but Don't React Method



David Stein, PysD, Pediatric Psychologist, New England Neurodevelopment, LLC, Concord, MA

Behavior problems impact approximately 30% of children with DS. Left untreated, these same children often exhibit behavior problems as adults, limiting work and independent living opportunities. In order

to address behavior problems effectively, one must understand the brain-based reasons for these challenges and direct treatment appropriately. This workshop will present the basic neuroscience of DS and how this informs effective behavior management, with practical strategies provided for use in the home and school settings.



25 **An Unprecedented and Exciting DS Research Discovery Engine – The Crnic Institute Human Trisome Project™**

Joaquin Espinosa, PhD, Executive Director, Linda Crnic Institute for Down Syndrome, Aurora, CO

This workshop will provide important information, in layman’s terms, about the Crnic Institute Human TrisomeProject™ — one of the most exciting DS research projects that aims to improve the health of children and adults with DS and millions of others who are affected by autoimmune diseases, Alzheimer’s, and cancer. Learn about new discoveries that recast DS as an immune system disorder and learn how self-advocates and local DS organizations can support this important effort.

26 **Understanding Special Needs Trusts and ABLE 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 ABLE 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.

27 **Tips for Getting the Most out of Your NDSC Adult Sibling Toolkit**



Tamara Pursley, Programs and Partnerships Director, NDSC, son with DS, Loganville, 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 a family working towards the same goal, as well as how to meaningfully include the sibling with DS in the process. Siblings will join the session to answer 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.



28 DS Along With Autism Spectrum Disorder: Recognizing the Signs, Understanding the Diagnostic Process, and Exploring Intervention Approaches



Nancy Raitano Lee, PhD, Assistant Professor & Director, Accelerated BS/MS and MS in Psychology Programs, Department of Psychology, Drexel University, Philadelphia, PA

This workshop will describe the signs and symptoms of ASD in children with DS. It will review the diagnostic process, including the tests that are given and the developmental considerations involved with evaluating ASD in children with DS. Video material will be utilized to illustrate the diagnostic process and the signs and symptoms of ASD. During the workshop, research on the learning and behavior challenges that may be experienced by children with this additional diagnosis will be discussed. Suggestions for the types of interventions that may benefit children with DS and ASD will be provided. Additionally, information about empirically-supported interventions for ASD will be described in order to introduce attendees to the types of approaches that may be helpful for children with DS and ASD.

29 Recomendaciones adicionales en los cuidados de salud en las personas con síndrome de Down

Esp

Karla Adney Flores Arizmendi y Lidia del Carmen Gomez Puente, *Pediatra/ Posgrado en Atención Integral a Personas con síndrome de Down, Instituto Nacional de Pediatría de la Ciudad de México, Jefe de la Clínica Down*

Previamente se han descrito las comorbilidades asociadas y los cuidados de salud de las personas con síndrome de Down, entre estas se encuentran las recomendaciones de la Academia Americana de Pediatría emitidas en el año 2011. En los últimos años se han adquirido nuevos conocimientos en materia de salud de las personas con síndrome de Down, por lo que se presenta este taller de actualización con el fin de complementar las recomendaciones previas. Se realizó una revisión narrativa de los temas que no han sido incluidos o que requieren actualización, entre ellos: hiperbilirrubinemia en el recién nacido, disfunción tiroidea, deglución, inmunidad, vacunas, hipertensión pulmonar, SAOS, diabetes mellitus, dislipidemias, hiperuricemia, vitamina D, estrés oxidativo y micronutrientes. Es de suma importancia el brindar herramientas útiles a los padres de familia para su integración en el seguimiento médico de rutina con el fin de lograr una mejor calidad en la atención de las personas con síndrome de Down.

SATURDAY, JUNE 29, 1:30 -3:00 PM

31 How to Teach Your Child Gross Motor Skills – Birth to Walking



Patricia Winders, PT, Senior Physical Therapist and Director of Therapies, Anna & John J. Sie Center for Down Syndrome at Children's Hospital Colorado, Aurora, CO

This interactive workshop will give you a systematic way to teach your child the gross motor skills from birth to walking. Demonstrations and hands-on experiences will help you learn when to teach your child these skills and how to practice them.

32 Don't Forget the Music! Get Them Talking When You Use It!



Eva Hampton, MA, CCC-SLP, Speech-Language Pathologist, Hampton Speech Therapy, son with DS, Spring City, TN

Ok, it's a given. Your person loves music, right? So, use it even MORE for improving speech and language skills. In this session, be convinced that music can be a catalyst for improving speech and language skills. Discussion will include factors to be considered when music is presented such as speed and volume, environmental setup, and visual and tactile cues. Learn to use music to target the following: prosody (up and down pitch inflections that are key to understanding language nuances), speech sound production (for clearer speech), rhyming identification and creation (pre-reading skills), language skills, and life skills. Where to find the music will also be discussed. Get ready to think outside the box and have some fun! No musical ability required!

33 Inclusion 101: Making Inclusion Happen



Sean Smith, PhD, NDSC Board Member, Professor, Department of Special Education, University of Kansas, son with DS, Lawrence, KS, **Jawanda Barnett Mast**, Blogger and Down syndrome Advocate, daughter with DS, Olathe, KS, and **Nolan Smith**, High School Senior and Self-Advocate, Lawrence, KS

How is it that while inclusion is at an all-time high, individuals with DS spend the majority of their school day in a resource or separate classroom from their typically developing peers? This interactive session will explore the environmental and instructional barriers confronting children and offer solutions. Focusing on high-leverage and effective practices, this interactive session will feature tips, strategies, and effective techniques proven to facilitate inclusion. Approaches to address literacy, social emotional, and behavioral interventions will be considered. Drawing from real-life experiences, this presentation will include perspective from parents, educators, and self-advocates.

34 Assistive Technology: Access for All



Laura Cantagallo, MS, NBCT, Assistive Technology Specialist and Outreach Coordinator, Temple University: Institute on Disabilities, Philadelphia, PA

The workshop will provide valuable information for how to incorporate assistive technology in the Individualized Education Program. Attendees will be led through an open-ended discussion about assistive technology, what it is, and ideas for how to use it with people with DS to improve independence in the school and community setting. The workshop will provide a review of assistive technology considerations and provide attendees with important questions to ask a school team when

considering assistive technology. Attendees will be grouped together to discuss the SETT framework and team-based collaborative decision-making with a focus on assistive technology.

35 Promoting Strengths and Adaptive Resources in Persons With DS



Dennis McGuire, PhD, Senior Consultant, Global Down Syndrome Foundation, Denver, CO



This session will look at creative ways to adapt to challenges of concrete forms of thought and behavior. These challenges can greatly limit communication, flexibility, and adaptiveness to change; create problems generalizing to new settings; and affect one's perception of time and humor. Discussion will include key behavioral characteristics such as 'grooves,' social sensitivity, visual memory, and visual cues and how they may be used creatively to compensate for the challenges of concrete thinking and behavior. Finally, how these characteristics may be used to solve a host of day-to-day problems and challenges which people may encounter in school and community settings will be addressed.

36 The Future of Inclusive Higher Education: Make Your Voice Heard!



Stephanie Smith Lee, Senior Policy Advisor, NDSC, daughter with DS, Charlotte, NC, and **Madeleine C. Will, MA**, Co-Founder and Interim President, Collaboration to Promote Self-Determination, Washington, D.C.

Postsecondary education opportunities for students with intellectual disabilities have greatly expanded over the past 15 years as a result of advocacy and improvements to the Higher Education Act, with now over 260 programs across the country. While the initial advocacy push was to open the doors to college, and substantial progress has been made, the field is now at the point of identifying and addressing “next generation” issues related to admissions, funding, desired outcomes, accountability, etc. National experts will provide an update on the state of inclusive postsecondary education and solicit comments on needed expansion and improvements. Input from this session will be shared with the Accreditation Workgroup currently creating model program standards and with the U.S. Department of Education.

37 Behavior News You Can Use!



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

Behavior can be frustrating and confusing, but the good news is that there is a science of learning and behavior that can help, no matter what age or stage a child is in. It is important to understand the basics of behavior to be able to apply them to a variety of situations. Participants will learn these behavior basics and effective strategies they can use to prevent and respond to a child's behavior.

38 **ABLE Accounts: A Down Payment on Financial Freedom**



Miranda Kennedy, MPP, Director of the ABLE National Resource Center, National Disability Institute, Washington, DC, **Rachel Mast**, ABLE Account Owner and Self-Advocate, Olathe, KS

Achieving a Better Life Experience (ABLE) accounts are tax-advantaged savings accounts for individuals with disabilities and their families. Eligibility for public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test. Both ABLE accounts and special needs trusts (SNTs) are forms of protected asset accounts. Each allows for the accumulation of money, for the benefit of an individual with a disability, without jeopardizing key federally-based benefits. This presentation will compare ABLE accounts with two types of SNTs: First and Third Party Non-Pooled SNTs. Discussion will focus on when either a SNT or an ABLE account might be the preferred vehicle for savings/asset accumulation. Rachel Mast, a 19-year-old with DS who was the first ABLE account owner in Kansas, and her mother, Jawanda Mast, will be sharing their experience with ABLE account ownership and what it means for their financial planning now and in the future.

39 **Down Syndrome Clinic to You (DSC2U): A New Virtual Clinic for All Families**



Brian Skotko, MD, MPP, Emma Campbell Endowed Chair on Down Syndrome, Massachusetts General Hospital, sister with DS, Boston, MA

Over 95% of individuals with DS in the U.S. do not have access to a DS specialty clinic. Researchers at Massachusetts General Hospital and Harvard Medical School have now created "DS Clinic to You" (DSC2U) as a way to bring the latest advances in health and wellness for people with DS directly to caregivers' home computers. With DSC2U (dsc2u.org), caregivers complete an online intake form where they identify current concerns about their son or daughter with DS. Their responses generate two personalized documents: a plan for caregivers and another one for the primary care providers of their son or daughter. Funded by a national PCORI grant, Dr. Skotko will review the efficacy and satisfaction results of more than 200 English and Spanish-speaking families who have already used DSC2U. This workshop will include a demonstration of DSC2U.

40 **Obstructive Sleep Apnea and Ear, Nose, and Throat Problems in DS**



Christine Heubi, MD, Assistant Professor, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

This presentation will review many of the common otolaryngologic (ear, nose, and throat) problems seen in children and young adults with DS. This includes chronic ear infections, hearing loss, chronic nasal congestion, sinusitis, and airway problems such as sleep abnormalities and obstructive sleep apnea. Medical and surgical treatment options will be discussed. The recent use of the hypoglossal nerve stimulator for treatment of sleep apnea will also be addressed.

41 Connecting Families and Those With DS to Research That INCLUDEs Them



Melissa Parisi, MD, PhD, Chief, Intellectual and Developmental Disabilities, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH), Bethesda, MD

The National Institutes of Health (NIH) has a longstanding program of research in DS. The Trans-NIH DS Working Group is now involved in a new NIH initiative called INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand DS). NIH staff and researchers will discuss the INCLUDE project (<https://www.nih.gov/include-project>) which was launched in June 2018. The directive calls for a new trans-NIH research initiative on critical health and quality-of-life needs for individuals with DS, focusing on co-occurring conditions such as Alzheimer's disease, cancer, cardiovascular disease, immune system dysregulation, and autism, among others. In addition, NIH staff will update attendees on new features in DS-Connect®: The DS Registry (<https://DSConnect.nih.gov>). Participants can also inform NIH and researchers about the issues that matter to them and share their research interests and priorities.

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, ABLE Act, and waivers. Focus will also include the importance of developing independence through the use of readiness assessment and goal development.

43 DS-ASD: Will My Child Always Wear Diapers? Understanding Toileting Challenges and Exploring Solutions



Terry Katz, PhD, Senior Instructor with Distinction, Children's Hospital Colorado, University of Colorado School of Medicine, Aurora, CO

This presentation will cover issues related to toileting including the challenges involved in toilet training children with special needs and useful and practical strategies to teach this important skill.

44 **Aprender a enseñar: Estrategias para apoyar a mi hijo/a en el proceso lector y de cálculo matemático**

Esp

Waleska Lisboa, Educadora Diferencial, especialista discapacidad cognitiva, Centro UC síndrome de Down, Pontificia Universidad Católica de Chile Santiago, Chile.

Actualmente las personas con síndrome de Down, participan del mundo escolar y laboral, por lo cual se hace necesario brindarles herramientas que les permitan mayores niveles de participación e inclusión. Es por esto, que es fundamental que los padres y educadores, cuenten con conocimientos y estrategias para promover mayores niveles de aprendizaje y desarrollo. Uno de los ámbitos que debemos considerar es el de las Habilidades académicas instrumentales, específicamente en los procesos de lectura y habilidades matemáticas.

Lo anterior es avalado por varios autores a nivel internacional, como son María Victoria Troncoso, es España y Sue Buckley en el Reino Unido, las cuales por más de tres décadas han analizado los procesos de aprendizaje de las personas con síndrome de Down, con el objetivo de proponer estrategias favorecedoras y acordes a su estilo de aprendizaje.

El presente taller buscar entregar herramientas prácticas y que puedan ser aplicadas desde lo cotidiano, para promover los procesos de literacidad emergente, lectura, escritura, comprensión lectora y adquisición de habilidades pre numéricas, número, operaciones matemáticas básicas y uso del dinero. Todo lo anterior basado en las autoras antes mencionadas y la experiencia práctica de apoyo directo a personas con síndrome de Down desde edades tempranas a la vida adulta.

SATURDAY, JUNE 29, 3:30 -5:00 PM

46 **How to Teach Your Child Gross Motor Skills – Post-Walking Skills**



Patricia Winders, PT, Senior Physical Therapist and Director of Therapies, Anna & John J. Sie Center for Down Syndrome at Children's Hospital Colorado, Aurora, CO

This interactive workshop will give step-by-step instructions to help teach a child the nine gross motor skills after walking including running, stair climbing, jumping, and riding the tricycle. Demonstrations and hands-on experiences will include when to teach a child these skills and how to practice them. Foot support options will also be discussed.

47 **The Journey to Communication**



Eva Hampton, MA, CCC-SLP, Speech-Language Pathologist, Hampton Speech Therapy, son with DS, Spring City, TN



The ability to communicate and connect trumps all skills. This session will review how to ensure the basic foundations of communication don't get missed, how to know what special factors to consider with DS, and how to improve understanding and use of words as well as speech clarity. The session will help identify what motivates a person and how to use these motivators to create opportunities for building on their current speech and language skills. How to be prepared for and USE the inevitable and

frustrating communication breakdowns that will happen on the road to being a good communicator will be demonstrated.



48 The Pee and Poo in You: A Three-Stage Physical Therapy Approach for Successful Toilet Training.

Helen Milligan, MPT, Physical Therapist, son with DS, Philadelphia, PA, and Mary Pipan, MD, Behavioral Pediatrician & Director, both from Trisomy 21 Program, Children's Hospital of Philadelphia, PA

The Trisomy 21 program at Children's Hospital of Philadelphia (CHOP) has developed a three-stage program to manage the challenges of toilet training and constipation. Helen Milligan, MPT is a pediatric pelvic floor therapist who utilizes a physical therapy approach in conjunction with medical management and an emphasis on nutrition, motility, and constipation interventions as part of our comprehensive clinic evaluation. The program prepares the child and family for toilet training with an evaluation and treatment of the pelvic floor muscles, abdominal and respiratory muscle training, constipation management, and postural control along with preventative and interventional medical management.

49 A Deep Dive Into IEPs



Ashley Barlow, Managing Partner, Meier & Barlow Law Firm, son with DS, Fort Thomas, KY

The IEP document can be extremely intimidating, but the laws that created it are designed to include parent participation. Ever wonder how to write a goal, how to differentiate between modifications and accommodations, or whether parent input matters when the school team starts rattling off data from "present levels of performance?" The session will take participants through the parts of the IEP that the federal law, IDEA, mandates be in every IEP and will provide specific examples that parents can keep in their toolbox at IEP meetings. Participants will also learn advocacy tools to encourage effective communication between the parents and school team.

50 Twenty Technology Tips & Tools for Effective Inclusion



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

The growth of technology in today's learning is phenomenal with increasing access to mobile devices, tablets, computers, and countless apps. Many of these digital solutions are altering the way our children learn, how teachers instruct, and how to navigate daily life. For individuals with DS, technology is enhancing their independence, providing access to learning and employment, and altering what can be accomplished in day-to-day life. This interactive session will focus on twenty technology tips and tools. Each tip or tool will be introduced, demonstrated, and then applied to an instructional or daily living task. All resources shared will be free or have an alternative tool that is free.

51 Alzheimer's Disease and DS



Huntington Potter, PhD, Director, Alzheimer's Disease Program, Linda Crnic Institute for Down Syndrome, Director Rocky Mountain Alzheimer's Disease Center, Professor and Vice Chair Basic Research, University of Colorado, Aurora, CO

People with DS invariably develop the pathology of Alzheimer's disease by age 30-40, and about half develop dementia by age 50-60. We have also discovered that people with Alzheimer's disease develop cells throughout their bodies with trisomy 21, linking these two disorders mechanistically. This workshop will consider the reasons why Alzheimer's disease develops in people with DS and in typical people and how this information is being used to develop new diagnostics and therapies for both populations.

52 What Happens When the School Bus Stops Coming



Michele Leahy, MS, CPWIC, Disability Life Planner, CEO, Leahy Life Plan, Conshohocken, PA



Hours have been dedicated to evaluations, therapy sessions, and IEP meetings; however, the school services are coming to an end. What will life look like for the loved one with a disability in 10 or 20 years? What about after parent caregivers are gone? What government services and programs are available and how does one connect them to both the family's and the individual's goals? What benefits are people with disabilities entitled to versus what are they eligible for? What is the difference between SSI, SSDI, Medicaid, and Medicare? What about planning for how a loved one will live when family can longer financially provide for them? Is it possible to find a loved one work without compromising their much-needed government benefits? These questions and more will be addressed in this session.

53 How to Ignite Your Own Life: Roadmap to Success



David Egan, Self-Advocate, Board Member and Community Relations Specialist, Down Syndrome Association of Northern Virginia, Oakton, VA and **Paul Eder, PhD, PMP**, Author, Lead Consultant, The Center for Organizational Excellence, Inc., son with DS, Rockville, MD

What is the difference between those bold enough to pursue their dreams and others who never ignite their lives? Looking for a way to make career dreams come true? Meet Paul Eder, co-author of "Firestarters: How Innovators, Instigators, and Initiators Can Inspire You to Ignite Your Own Life," and join David Egan as he describes his road map to success. They will share tips for parents and self-advocates to land jobs and venture on their journey in pursuit of a career. In addition, David will also share resources for employers to make employing individuals with DS a good business investment. David and Paul will have participants leave feeling empowered to become part of an inclusive workforce.

54 Updates in Medical Care: The Down Syndrome Medical Interest Group-USA



Peter Bulova, MD, President, DSMIG-USA, Pittsburgh, PA, Maria Stanley, MD, Vice President, DSMIG-USA, Madison, WI, and Marilyn Bull, MD, Board of Directors, DSMIG-USA, Indianapolis, IN

DSMIG-USA is a group of health professionals, now in their 25th year, committed to promoting optimal health care and wellness of individuals with DS across the lifespan. They will share information from their symposium that meets just prior to the convention. Over 100 medical professionals are in attendance who have both an interest and expertise in caring for those with DS. This workshop will share medical advances presented at the symposium, as well as opportunities for families to become involved in advancing medical care for those with DS.

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



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.

56 Ten Basic Financial Steps for Special Needs Caregivers



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.

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.

58 DS-ASD: Sleepless Children and Exhausted Parents – Understanding Sleep Problems and Exploring Solutions



Terry Katz, PhD, Senior Instructor with Distinction, Children's Hospital Colorado, University of Colorado School of Medicine, Aurora, CO

This talk is designed for parents and providers who want to learn more about sleep, why children with special needs may have difficulty sleeping, and what they can do to help everyone in the family sleep better. The session will be informative and practical, providing families with ideas that they can use at home.

59 De la menstruación a la masturbación - abordar la pubertad en niños con síndrome Down sin frustración

Esp

Noemi Alice Spinazzi, MD, Médico de Cabecera en UCSF Benioff Hospital de Niños en Oakland; Directora Medica de la Clínica de Síndrome de Down en UCSF; Co-Directora de Rotación de desarrollo pediátrico y conducta en UCSF Benioff Hospital de Niños Oakland; y Profesor Clínico Asistente en Escuela de Medicina en UCSF

La pubertad es un tiempo tumultuoso caracterizado por cambios externos del cuerpo, la evolución de sentimientos fuertes, y el deseo de autonomía. Los padres de niños con síndrome de Down deben saber cómo hablar sobre la pubertad con sus hijos, a fin de prepararlos para estos cambios, ayudarlos a ser cada vez más independientes con su autocuidado y ayudarles a reconocer situaciones potencialmente peligrosas. Esta charla, inspirada en los libros de Terri Couwenhoven, proporcionará una visión general de cómo hablar a los niños sobre la pubertad.

61 123s and More – Creating a Strong Math Foundation



Dana L. Halle, JD, NDSC Board Member, Executive Director, Down Syndrome Foundation of Orange County, son with DS, Orange County, CA

This session will provide participants with evidence-based strategies, resources, and activities for teaching counting, place value, addition and subtraction to learners with DS. Activities will be illustrated with pictures and video examples from students in Down Syndrome Foundation’s The Learning Program™ and After School Academy™.

62 Toddlerhood to Transition: Top Ten Tips for an Amazing Future



Emily Jean Davidson, MD, MPH, RYT, Attending Physician, Director of Prenatal Care, and **Angela Lombardo**, Program Coordinator, both from Boston Children's Hospital Down Syndrome Program, Boston, MA

This session will focus on setting the groundwork to build a strong foundation from infancy through teens in order to thrive in adulthood. From a 23-year old young man with DS, his mother (who is the Program Coordinator for the Boston Children's Hospital DS Program), and an attending pediatrician in the BCH DS Program, explore their top ten building blocks to thrive in adulthood. From infancy to young adults, they will take a lifespan approach to developing competence in communication, best behaviors, skills, literacy, healthy habits, exercise, community-building, friendships, advocacy and self-determination, and work and volunteering. The seminar will be packed with practical tips for each age period.

63 Take a Peek! Video Modeling and Video Instruction: A Power Tool for Learning Stuff!



Lindsay M. McCary, PhD, Licensed Psychologist, Director of the Autism & Developmental Disabilities Clinic, and **Elizabeth M. Delsandro, MS, CCC-SLP**, Senior Speech-Language Pathologist, both from The Waisman Center, University of Wisconsin-Madison, WI

For children who frequently need to be guided through activities with multiple steps or desire to complete an activity independently but still need help, video modeling might be the power strategy to move towards more independence and gain pride in getting the job done. Video modeling is a strategy to teach a child a variety of skills at home and in the community, such as feeding a family pet, getting ready in the morning, writing a thank you card, or ordering at a restaurant. This workshop is designed to provide an overview of the evidence or research that supports the use of video modeling, to introduce different types of video modeling, and to also give tips and tricks for getting started making videos. Let's get started – lights, camera, action!

64 Challenging Goals and High Expectations for Every Child



Jeannine Brinkley, MEd, Executive Director, and Cindy Duch, Director of Parent Advising, both from PEAL Center, Pittsburgh, PA

This session will review the positive implications of the Endrew F. decision by the Supreme Court of the United States that both families and educators need to understand. The session will identify key elements of the evaluation, re-evaluation, and IEP processes, and how these elements can facilitate access to the general curriculum and high expectations for students with complex needs. Tools that can be used in developing and reviewing IEPs will be shared.

65 The Improvaneers! How the World's First All-DS Improv Troupe Will Be a Game-Changer for Improving Job and Social Opportunities!



Rob Snow, Founder, Director/Producer, Professional Speaker, Author, Stand Up for Downs, son with DS, Medina, OH

In 2017, Stand Up For Downs had an idea to teach improvisation to those with DS in the hopes that it would build skills that could help enhance social and workplace opportunities. What started as a monthly program grew to much more. The Improvaneers were formed in 2018 and are the world's first all-DS improvisation troupe! They have been training to learn stronger communication skills such as eye contact and projection. Training has built self-confidence, quick-thinking and problem-solving skills; taught the importance of team work; and has unlocked creative doors that had never been opened. This session will be informative, eye-opening, interactive, and very fun. It will show the results of the program through video, live performances, and audience participation.

66 Can My Child Learn to Drive? Teaching and Assessing Driving Skills for Individuals With IDD



Joseph Ryan, PhD, Executive Director, and Erica Walters, MS, Coordinator, both from ClemsonLIFE (Learning is for Everyone), Clemson University, Clemson, SC

Obtaining a driver's license has become a cornerstone of independence and represents a major step towards becoming an adult in modern society. Being able to drive enhances one's ability to capitalize on quality jobs and expands one's access to other opportunities, including personal independence and community services. Learning how to drive and having accessible transportation have continued to serve as barriers for individuals with disabilities, particularly those with an intellectual disability. Fortunately, the advancement of driving simulators has enabled a safe and cost-effective method for teaching and assessing driving behaviors under a host of conditions. This workshop will provide an overview of the research and methods used for teaching and assessing basic driving skills for individuals with disabilities. ClemsonLIFE (Learning is for Everyone) is a post-secondary education program that has collaborated with the International Center for Automotive Research to develop a curriculum to teach and assess driving skills for young adults with IDD.

67 The Soul Sisters Return



Michelle & Tanya Ponich, sisters, Edmonton, Alberta, Canada



Sisters by birth and soul sisters by choice, The Soul Sisters Return take participants through the journey of their lives together. Tanya, an advocate with DS, shares her views on life, her family, and what it is like being a 40-year-old woman with DS in today's world. Michelle, Tanya's older sister, speaks candidly about Tanya, their family's journey, and the deep bond they share. They will speak of the challenges and adversity they have faced and how these experiences have made them into the women they are today. This session promises to inspire, give hope, and give suggestions on how to handle life's curve balls with love and a big dash of humor.

68 Your Story. Your Voice. You Make the Difference.



Heather Sachs, JD, Policy & Advocacy Director, NDSC, daughter with DS, Potomac, MD, and **Jawanda Barnett Mast, MS**, Disability Rights Advocate, daughter with DS, Olathe, KS, **Rachel Mast**, Self-Advocate and College Freshman, Olathe, KS



It is important for elected officials to understand why issues such as inclusive education, meaningful employment opportunities, comprehensive health care coverage that does not discriminate, and transportation and housing options for people with DS should be affordable and abundant. This workshop will give you the tools, resources, and training necessary to become an advocate for policy change. The NDSC Policy Team along with self-advocates like Rachel Mast will guide participants on the advocacy journey. The workshop will cover what grassroots advocacy entails, how to build relationships with elected officials, and how self-advocates can become meaningfully engaged in grassroots advocacy efforts. Individuals with DS, family members, and professionals in the DS community are all encouraged to use their voices to promote change. Voices are more powerful when they are united!

69 Dr. Jen's Top Ten: Activities for Excellent Balance, Coordination, and Confidence in Movement



Jennifer Spiric, PT, DPT, Doctor of Physical Therapy, Lead Pediatric PT, and **Sarah Mann, PT, DPT, MBA**, Doctor of Physical Therapy, both from Mann Method Physical Therapy and Fitness, PLLC, Arvada, CO

This PT-developed workshop is designed to be an interactive, hands-on learning experience for children, parents, and therapists. This is a chance to learn and practice ten fantastic new sensory-motor activities to help children achieve gross motor milestones, decrease risk for falls and injury, and improve confidence with age-appropriate mobility skills. These activities help the body's inherent balance systems work together to improve balance and coordination. Best of all, they are fun and easy, and you can start doing them today!



70 CPAP, Hearing Aids, and Glasses, Oh my! How to Help My Child Wear Their Medical Equipment

Lina Patel, PsyD, Director of Psychology, Sie Center for Down Syndrome, Children's Hospital Colorado, Aurora, CO

This presentation will provide a step-by-step guide on how to help children with hearing loss, vision problems, and apnea learn to use their medical equipment. Common challenges will be reviewed in addition to strategies to overcome those challenges.



71 Brain Train: SMART Actions That Might Boost Cognition and Prevent Alzheimer's Disease in People With DS

Brian Skotko, MD, MPP, Emma Campbell Endowed Chair on Down Syndrome, Massachusetts General Hospital, sister with DS, Boston, MA

Two of the most common yet challenging questions that Dr. Skotko is asked by caregivers are how to prevent Alzheimer's disease in people with DS and how to boost cognition. While exciting research is unfolding in laboratories across the world, there are strategies that caregivers can take right now with respect to these two questions. In this presentation, Dr. Skotko reveals his recommendations, which must meet all of the following criteria: (a) supported, in part, by quality science (b) have practical applications for home (c) be adaptable to people with DS (d) pose no risk to people with DS. This is not a presentation on how best to educate people with DS or about supplements and nutraceuticals. Instead, Dr. Skotko provides a set of actions that caregivers can take that might improve the long-term wellness for their loved one with DS. Attendees will come away with immediate steps that can be implemented in their homes.

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.

73 Common Behavior Issues in Children With DS + ASD



George Capone, MD, Director, Down Syndrome Clinic and Research Center, Kennedy Krieger Institute, Baltimore, MD



It is recognized that children with DS + ASD have especially complex needs because of the constellation of medical-developmental-behavioral challenges they face. In this session, we will describe several factors that contribute to how children with DS + ASD express their behavior. Maladaptive behavior will be discussed, providing an understanding and problem-solving strategies to manage internalizing (autism-like), externalizing (disruptive), or mixed behavior features (both). The physiologic underpinnings of sleep, mood, and attention/activity regulation will also be emphasized. A comprehensive program usually involves combining strategies across several disciplines simultaneously as each approach may have something to contribute. In situations where difficult behaviors have become entrenched, it may still be possible to discover what's missing from the program in order to make life better for you and your child.

74 Formando Conductas Adaptativas para la vida



Silvia Maravilla Ávila y José Alberto Alonso García, Lic. en Psicología, especialista en Terapia Familiar, API, Centro de Asesoría Psicológica Integral

Los hábitos y rutinas se moldean con las actitudes y comportamientos de los padres en la formación de las personas con síndrome de Down.

La conducta adaptativa se desarrolla a lo largo de la vida. La constancia y congruencia de los padres a la hora de establecer los hábitos y rutinas son clave del éxito adaptativo de las personas con síndrome de Down.

El objetivo de este taller es que el padre adquiera estrategias para establecer conductas y comportamientos funcionales desarrollándolas a través de reglas rutinas y hábitos.

Es importante que el padre practique esta formación con su hijo en el día a día para lograr que la persona con síndrome de Down se desenvuelva funcionalmente dándole así mayor adaptabilidad en su entorno social.

75 Promoting Optimal Health for Children With DS



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

Evidence-based healthcare for people with DS is a relatively new phenomenon. 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 healthcare providers. This workshop is intended to empower caregivers to know about the medical issues that are more common in people with DS in an easily understood presentation. NDSC President Dr. Vellody will focus on the medical issues seen in children and adolescents and how the American Academy of Pediatrics Healthcare Guidelines are designed so people with DS can live healthier and happier lives. There will be a brief time for audience questions following the presentation. There is also the option for audience interaction during the presentation through the Poll Everywhere app (download for free on the iTunes and Google Play stores).

76 Awareness, Preparedness, and Prevention: Safety Issues for Children With Special Needs



Alyssa Siegel, MD, *Clinical Assistant Professor of Pediatrics, Perelman School of Medicine at the University of Pennsylvania, The Children's Hospital of Philadelphia, Philadelphia, PA*

Children with DS may have specific vulnerabilities that heighten parental concerns regarding safety. Medical issues such as hearing and vision impairment or gross and fine motor challenges may obligate home modifications to reduce the risk of common household hazards. Individuals with a limited sense of danger may need safeguards against impulsivity in public places, in traffic, or around bodies of water. Those with a trusting nature or who have difficulty understanding social boundaries may need special precautions to prevent abduction and exploitation. Fire safety, elopement, bullying, internet pitfalls, sexual abuse – there should be no topic too daunting to consider. By reviewing strategies to secure a child's environment and being armed with tools to help teach children about safety, this session will provide a foundation to prepare for life's daily perils.

77 Using Both Speech and AAC to Support Communicative Independence



Kathryn Helland, MS, CCC-SLP, *AAC Services Coordinator, Temple University's Institute on Disabilities, Philadelphia, PA*

Augmentative and alternative communication (AAC) can be a powerful tool when someone has difficulty being understood. People can speak and still choose to use AAC. Research shows that people with DS have more difficulty being understood by unfamiliar communication partners or when speaking longer sentences. Even if their speech is understood by those who know them well, it may still be of benefit to use AAC. Increasing someone's communicative independence can have a big impact on their ability to

find employment, talk with healthcare professionals, and self-advocate. AAC devices and apps provide a range of features to meet individual needs, from symbol-based communication to text-to-speech. AAC is portable: it can fit on a smartphone! It can also be used to activate virtual assistants, such as Alexa or Google Home. This workshop will also describe some of the major resources for funding the acquisition of AAC devices.

78 Accessing the Curriculum



Dana L. Halle, JD, NDSC Board Member, Executive Director, Down Syndrome Foundation of Orange County, son with DS, Orange County, CA

This session will focus on adaptations to curriculum, assessment, environment, and instruction to enhance learning. Adaptations enable students with DS to learn using the general education curriculum with its rich content.

79 Effective Team Approach for Inclusive Education Within a School District – Perspectives From Team Members



Frank T. Gallagher, EdD, Superintendent of Schools, **Jon Graf, EdD**, Principal, Vernfield Elementary School, **Megan Zweiback**, Director of Pupil Services, and **Michelle Noga**, Elementary Special Education Supervisor, all from Souderton Area School District, Souderton, PA

This will be a panel discussion, including a questions and answers segment, with the Superintendent of Schools, Director of Pupil Services, Supervisor of Special Education and an elementary Principal from the Souderton Area School District, Souderton, PA. The panel will focus on how the District has individualized inclusion opportunities for students with DS. Panelists will offer their philosophy and perspectives on programming for students with DS at their different levels of district. The panel will discuss the multiple facets of effective inclusion including: student engagement, school community, assessment, related services, modifications and adaptations of curriculum, social skills, behavior, and least restrictive environment from elementary age through post-secondary transition age.

80 Movin' On Out



Carrie Bergeron, Self-Advocate, Fairport, NY, and **Katie Bergeron Peglow, PT, MS**, COO - *Adaptivemall.com, LLC*, sister with DS, Dolgeville, NY

It is important to transition caregiver roles from one person to another when everything is good and everyone is doing well...not in the middle of a challenging time. For Carrie, the transition of caregiver roles from her parents to her sister, Katie, started with the move from her own apartment 45 minutes from her parents to one that was a mile from her sister. Katie is now on call for Carrie instead of mom and dad who are now 2.5 hours away. Come and learn about the challenges of transferring services from one county to another; finding safe and affordable housing; and identifying programs, classes and community opportunities to participate in.

81 Making the Most of a Behavioral Health Consultation for Adults With DS



Bryn Gelaro, LSW, Director of Adult Initiatives and Special Projects, and Dennis McGuire, PhD, LCSW, Senior Consultant, both from Global Down Syndrome Foundation, Denver, CO

Finding a provider who can appropriately assess mental wellness and behavioral health in adults with DS is a common concern for families and self-advocates. In this session, we will discuss what to expect and how to prepare families, caretakers, and self-advocates for behavioral health consultations with their local providers. There are things that should be looked for before, during, and after an appointment to make sure adult self-advocate's behavioral health consultation is useful and informative. In addition, a review of common behavior characteristics of adults with DS will be presented, as well as how these behaviors can be used to support overall wellness and channeled into strengths. Through increased awareness about the process, families and self-advocates will leave the session feeling more comfortable talking about behavioral health with their medical provider and better prepared to advocate for their own mental wellness!

82 Tools to Support a Future Plan



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

Planning for the future is important for all families. Experience shows that adults with intellectual disabilities make a better transition from the family home when a future plan is in place. Some families might feel that planning is not available to them because they don't have any money to leave to an adult son or daughter with intellectual disabilities or can't afford a lawyer or an estate planner. This is not true. There are many aspects of the planning process that aren't related to money. Staff from The Arc's Center for Future Planning will provide an overview of the resources available that support families to create a future plan.

83 Why Is My Child Reacting This Way? Understanding Your Child's Sensory System



Monica Purdy, MA, CCC-SLP, Instructor, Talktools, North Charleston, SC

This presentation will focus on giving parents and caregivers an overview of the eight different sensory systems of the body and how these systems affect their children every day. Participants will be given examples of how to interpret the reactions to the sensory input and what is a typical versus atypical reaction. Parents will learn specific activities to help their child achieve success, as well as when to seek professional help and what type of help is available.

84 Valued Roles Can Lead to the Good Things in Life - Four Families Combat Devaluation



Guy Caruso, PhD, FAAIDD, Western Coordinator, Institute on Disabilities, Temple University, Baden, PA, and **Candy Vazquez**, Parent Advocate/Consultant, Pittsburgh, PA, **Ann Marie Licata, PhD**, Director of PA Inclusive Higher Education Consortium, Millersville

The importance of valued roles for all people can lead to the "good things" in life. To discourage the negative roles families often get led into with their child with a disability (such as pity/charity, illness/sickness, eternal/forever child, dependent, client/consumer), families and people with disabilities need to embrace valued roles that emphasize a person's skills, talents, abilities, and interests rather than their limitations and problems. This session will explore valued versus devalued roles with a presentation from four families who will share their child's valued role journey, and the strategies they used to avoid devalued roles so their child could experience the "good things" in life.

85 From Power Struggles to Powerful Partnerships: Understanding and Managing Challenging and Unsafe Behaviors



Nicole Baumer, MD, Director, sister with DS, Boston, MA, and **Cara Soccorso, PsyD**, Child Psychologist, both from Boston Children's Hospital Down Syndrome Program, Boston, MA

Behavioral challenges are common in individuals with DS. Without intervention, behavioral challenges can interfere with positive relationships and successful participation in recreation, education, vocation, and community living. This presentation aims to help parents better understand and manage their child's challenging behaviors. Neurodevelopmental differences in DS will be reviewed along with positive behavioral support strategies and evidence-based interventions. There will be an emphasis on professional evaluation and treatment of aggressive and unsafe behaviors, including pharmacological treatments.

86 Introduction to Inclusive Higher Education



Stephanie Smith Lee, Senior Policy Advisor, NDSC, Chair, Think College Accreditation Workgroup, daughter with DS, Charlotte, NC, 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.

87 Multidisciplinary Advocacy for Children Dually-Diagnosed With DS and Autism Spectrum Disorder: From Diagnosis Through the Lifespan



Mary Pipan, MD, Behavioral Pediatrician & Director, **Audrey Vincent, MSW, LSW**, Social Worker, both from Trisomy 21 Program, Children's Hospital of Philadelphia, PA, and **Diane Perry**, Parent Advisor, The PEAL Center, son with DS, Philadelphia, PA

This session will discuss the developmental and behavioral aspects of Autism Spectrum Disorder in the context of Down syndrome. Individualized supports based on the child's strengths and challenges will be addressed such as home-based behavioral support utilizing Applied Behavioral Analysis approaches, outpatient behavioral and therapeutic resources such as speech or occupational therapy, educational autism support in the least-restrictive settings with the appropriate behavioral and therapeutic supports, and day-to-day support to maintain the child's daily needs and safety. The utilization of an interdisciplinary team including a developmental pediatrician, social worker, and physical and occupational therapists will be reviewed. Through team collaboration and care coordination, the goal is to support families in advocating for their child's needs at each stage of life so they can reach their highest potential.

88 Síndrome de Down: Vida Dependiente vs Vida Independiente

Esp

Teresa Aguilascho, Médico Ginecologa, Lic. en Psicología, Tanatologa Familia, Salud y Desarrollo en Síndrome de Down A.C.

Hay cierta tendencia y características de la conducta en personas con discapacidad intelectual, del 12% al 14% presentan alguna dificultad de conducta, se observa más dificultades de conducta que niños regulares de la misma edad. Afortunadamente estas dificultades de conducta se reducen con la edad en la mayoría de los casos si se les da una atención asertiva y adecuada, y del 11% y 15% muestran dificultades consistentes de conducta hasta la edad adolescente. Hay ciertas entidades que favorecen estos trastornos de conducta, son identificables, entre ellos, desórdenes de sueño es la mayor causa de dificultades de conducta durante el día. Y los factores que influyen la conducta tenemos:

- Temperamento y personalidad
- Estilos y expectativas de los padres
- Estilos y expectativas del maestro
- Clima emocional
- Sentimiento de seguridad
- Sentimiento de ser valorado y amado en casa
- Sentimiento de ser respetado en la escuela
- Habilidad de comprender la expectativa en una situación determinada
- Habilidad de comunicarse de manera efectiva y eficiente
- Reacciones de los demás ante su propia conducta
- La formación y educación de las personas con síndrome de Down es un trabajo complejo, las altas y bajas, los momentos felices y tristes son magnificados.
- La felicidad de cada logro y las preocupaciones de cada reto es una constante día a día.
- La paternidad de niños con discapacidad, requiere niveles muy altos de amor, paciencia, fortaleza interna y de pareja.

Por lo que contribuir a la armonía familiar es el objetivo de este taller.



Birth-5



School Age



Teen Adult



All Ages



DS-Autism Track



Adult Sibs Track



Transition Track



Delivered in Spanish



Interpreted