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## PLENARY SESSIONS

### A Friday Evening Opening Session

#### **Creating a Better World for People with Special Needs**

**Gordon V. Hartman**, philanthropist, father of a daughter with special needs, San Antonio, TX

Gordon Hartman is a philanthropist and former businessman who was born and raised in San Antonio. At age 15, while attending a local seminary, he started his own landscaping business. By age 19, he had earned and saved enough to begin his homebuilding business and by the age of 23 had started a land development company. Over the next 22 years, he grew his company into the largest locally owned homebuilding and land development enterprise in San Antonio. In 2005, he established The Gordon Hartman Family Foundation to pursue his dream of helping children and adults with special needs. In 2010 he opened Morgan's Wonderland, the world's first ultra-accessible family fun park designed for kids with special needs. Later this year he will open Monarch Academy which will provide students with special needs a unique learning environment. His devotion to this cause is inspired by his 17-year-old daughter, Morgan, who was born with cognitive and physical special needs.

#### **Growing Up In Holland: A Sibling's Report From The Front Lines**

**Jenni Newbury**, Co-founder, Camp PALS, Education Resource Manager for Special Olympics Project UNIFY, sister of a brother with DS, Washington, DC.

Jenni is the co-founder of Camp PALS, a weeklong sleep away camp for young adults with Down syndrome. Camp PALS has been recognized by both the NDSS and the NDSC over the past 8 years and this summer hosted 113 campers and a full staff of 150 volunteers, all under the age of 25. Jenni is a graduate of Princeton University, where she majored in psychology and elementary education. During her time at Princeton, Jenni founded Princeton

Disability Awareness which hosts an annual Down Syndrome Conference that welcomes 500 families and their children with Down syndrome to campus each fall. She completed her senior thesis on the impact of having a sibling with Down syndrome and continues to support the development of new Princeton Disability Awareness initiatives. Jenni now works as the Education Resource Manager for Special Olympics Project UNIFY. Above all else, Jenni is a sibling to Jason Newbury, a self-advocate. It is this role that has defined and sculpted her life and it is Jason's strength that continues to challenge her to do more.

#### **Living My Dream: A Life Filled with Glee!**

**Lauren Potter**, Self-Advocate, Actress on Fox Television's Hit Show, "Glee", Riverside, CA

An inspiration to all, Lauren Potter has proven herself a young woman of strength and of character. Born into a family of three boys, she was blessed to have the playful and gentle guidance of loving brothers. As she grew, their influence stayed with her - making her a social genius and a skilled comedian. Lauren danced before she could walk. At age three, Lauren was in her element from her first dance class. For thirteen years, she loved to dance and craved the stage. She made her acting debut in the film "Mr. Blue Sky", playing the part of young Andra Little. Her acting skills impressed the producers of "Glee" enough that they offered her the part on the hit Fox television program. Playing the recurring role of Becky Jackson continues to open those doors for Lauren, and she hopes these doors will open wider still!

### B Saturday Afternoon Session

#### **Stand Tall, Be Diligent and Find Support**

**Michael Remus**, MS, Director of Student Support Services, Deer Valley Unified School District, Phoenix, AZ

Michael Remus has been a general education teacher, special education teacher, school principal, college instructor, special education director for a school district, state special education director for the State of Kansas, and is also the parent of four children, two of whom have disabilities. Currently he is Director of Student Support Services for Deer Valley Unified School District in Phoenix, AZ. Most of his professional career has been in the classroom and in training parents and educators. He is co-author of seven books for parents on how special education works, two training curricula based his books, two effective practices manuals on special education for



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schools, a toolkit with the administrative tools needed to make inclusive education successful and a Disability Awareness Activity Packet for teachers.

### **Building a Life on their Terms**

**Monica Walters Martinez & David Martinez**, Self-Advocates, Stars of HBO Documentary, *Monica & David*, FL & **Alexandra Codina**, Director & Producer

Monica and David are a married couple who star in the documentary that tells the story of two adults with Down syndrome who get married. It is about their courtship and their married life together. But the documentary is also about what it's like to be a parent of someone with an intellectual disability. The film is directed by Monica's cousin, Alexandra Codina. The film uses intimate fly-on-the wall footage to reveal the complexity of their story. "Ultimately, it's about independence, independence with the support." Monica & David won Best Documentary at last year's Tribeca Film Festival. After airing on HBO in October, Monica and David have been traveling with Codina to attend special screenings of the film around the country as well as doing interviews. The Martinezes are now pursuing acting careers.

### **C Sunday Morning Session**

**True Confessions of a Bully**, performed by Dionysus Theatre Group, Houston, TX

Written and Directed by Deborah Nowinski, Founding Artistic Director, Dionysus Theatre and the Commissioner of Houston's Commission for People With Disabilities. Dionysus Theatre is a non-profit theater organization that brings actors with and without disabilities together in the theater venue. This seven member inclusive cast touches upon cyber-bullying, name calling and harassment through the eyes of a bully and those he bullied. This powerful performance will enlighten, empower and entertain the

whole audience.

### **My Dad and Me**

**Christopher Scott**, Self-Advocate, Actor, Houston, TX

Christopher, along with Donovan Jennings, are the first African American actors with Down syndrome to star in a feature film, *My Brother*. At the 2006 HBO American Black Film Festival, The Founder's Award for Outstanding Achievement in Independent Cinema was awarded to Christopher Scott for his role in the film. *My Brother* is a film directed by Academy Award nominee Anthony Lover and the story of two impoverished boys, one of whom is developmentally disabled, and the bond of love they have for each other. "Christopher, who is featured in NDSC's "We're More Alike than Different" mini-documentary, is currently employed as a teachers' assistant at the Rise School of Houston."

## **WORKSHOPS: JULY 6, 8:30 AM**

### **01 Behavior and Communication: Promoting Positive Behavior Change**

**Scott Shepard**, MA Ed, Co-Director, Avenues Supported Living Services and professor, California State University, Northridge, North Los Angeles, CA

In this session participants will receive an overview of functional behavior assessment and positive behavior support; learn how to identify behavioral motivations, how to identify and teach replacement behavior and skills as an alternative to challenging behavior, and will acquire a variety of "tools" to assist in identifying why behaviors are occurring. These principles can be applied with children and adults of all ages and abilities.

### **02a Addressing Speech Motor Planning Disorders (Childhood Apraxia of Speech) in Children with DS – Part 1**

**Renee Roy Hill**, MS, CCC-SLP, TalkTools Therapy, Lecturer and Crossroads Therapy Clinic, New Braunfels, TX

This course is designed to address the challenges facing families of children and young adults with motor speech impairments related to



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apraxia of speech. Apraxia of speech is often difficult to identify in a child with other co-existing diagnoses, and is often masked by other developmental delays and challenges. Participants will learn how oral motor skills, sensory processing and motor planning skills interact, and how treatment may differ for those with difficulties in multiple areas of speech and motor development. The presenter will discuss identification markers for each area, ways to address these deficits and how to develop a holistic treatment plan that best fits the individual. Participants will learn that skills can be addressed at any age using a hierarchical approach.

### **02b Addressing Speech Motor Planning Disorders (Childhood Apraxia of Speech) in Children with DS – Part 2**

### **03 Latest Legislative Developments: How They Impact You!**

**Susan Goodman**, JD, Governmental Affairs Director, NDSC, mother of a son with autism, Olney, MD

Federal legislation directly impacts education, community living, housing, support services and employment for individuals with DS and their families every day. This session will offer parents the opportunity to learn how these laws affect their family and the future and how what is happening in Congress directly impacts their lives. We will be discussing the budget crisis and the threat to services for people with disabilities, latest developments in the education laws, prospect for improving employment outcomes for individuals with disabilities and health care updates. We will also talk about what families and advocates can do to make sure their voices are heard!

### **05 What Your Other Children are Thinking: Sibling Issues**

**Brian Skotko**, MD, MPP, Clinical Genetics Fellow, Down Syndrome

Program of Children's Hospital Boston, brother of a sister with DS, Boston, MA, and **Susan P. Levine**, MACSW, Social Worker, Family Resource Associates, Shrewsbury, NJ

Through discussion and a series of interactive exercises, parents will explore the questions, needs, and concerns often raised by children who have a brother or sister with DS. Parents and professionals will come away with practical answers to commonly raised questions. This presentation draws upon Brian Skotko's and Sue Levine's publication in the American Journal of Medical Genetics and their new book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*.

### **06a DS Registry, Research Database and Biobank – Part 1**

**Edward R.B. McCabe**, MD, PhD, Executive Director, and **Linda L. McCabe**, PhD, Bioethics & Community Outreach, both with Linda Crnic Institute for Down Syndrome, Aurora, CO

This workshop will describe the role of a DS registry, research database and biobank, and explain the importance of all three of these. Representatives from The Linda Crnic Institute for DS (LCI) at the University of Colorado will discuss how this information is requested and collected as well as how it will be used. The LCI is focused on eradicating the medical and cognitive ill effects of DS and is the first organization to include basic research, translational research, clinical research and clinical trials along with clinical care and advocacy. Time for questions and answers will be allotted.

### **06b DS Registry, Research Database and Biobank – Part 2**

### **07 Occupational Therapy — OT Doesn't Stand for the "Other Therapy"**

**Katie Frank**, MHS, OTR/L, Thomas Center for Down Syndrome at Cincinnati Children's Hospital Medical Center, Cincinnati, OH

This workshop is geared toward parents, caregivers, and professionals who have individuals with DS in their lives, ages birth to school age. This workshop will explain what Occupational Therapy is and its role



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And purpose in enhancing the child's life. The OT will present on current research to establish fine motor and self-care milestone norms for individuals with DS. The presentation will also cover specific treatment ideas and objectives to address a multitude of deficit areas to include fine motor development, handwriting, and feeding.

### **08 Teaching Reading to Teach Talking: See and Learn**

**Frank Buckley**, CEO, Down Syndrome Education International/USA, United Kingdom, brother of a sister with DS

This presentation aims to provide practical knowledge and skills to help participants successfully teach reading skills to children with DS, with additional benefits in speech, language and memory development. It explains how to use the "See and Learn" language and reading program.

### **09a Count Me In: Best Practices for Building an Inclusive Classroom Community – Part 1**

**Michael Remus**, MS, Director of Student Support Services, Deer Valley Unified School District, Phoenix, AZ

The session will cover steps parents can take to have their children participate with typical peers to build an inclusive community within the general classroom and learning center. It will define what inclusive practices are and the service delivery model to meet the continuum of services for each unique child. The participants will be provided questions they can ask at IEP meetings to (hopefully) secure a more inclusive environment and strategies to help them both in the academic and behavioral areas.

### **09b Count Me In: Best Practices for Building an Inclusive Classroom Community – Part 2**

### **10 Why All the Fuss About Working Memory?: Activities and Classroom Support to Enhance Learning**

**Dana Halle**, JD, Co-founder and Executive Director, Down Syndrome Foundation of Orange County/Downs Ed USA, mother of a son with DS, Newport Beach, CA

Why do researchers talk about visual learning strengths for children with DS? Why is learning from listening alone difficult? Join us as we explore working memory and what we know about how weaknesses in memory can impact learning. We will have fun testing our own memories and provide interesting and simple activities for home or school to improve your student's memory.

### **11 Promoting Health, Independence, Safety, and Community for Teens and Adults with DS**

**Brian Chicoine**, MD, Medical Director and **Dennis McGuire**, PhD, Director Psychosocial Services, Adult DS Center of Lutheran General Hospital, Park Ridge, IL

Find out how to help teens and adults become their own self advocates related to health care issues. This session will reiterate the association between mental and physical health and discuss treatment options such as the effective use of visual cues. Learn how to promote independence, how to promote success and adaptive skills and how to target specific community weaknesses. Finally participants will learn to differentiate "autistic features" from autism and why sex education is so important. The most recent health and psychosocial findings from the Adult DS Center will also be shared.

### **12 College Options for Students with Intellectual Disabilities**

**Debra Hart**, MS, Director and Meg Grigal, PhD, Co-Director, Department of Education & Transition, Institute for Community Inclusion, University of Massachusetts, Boston, MA

College is an option for students with intellectual disabilities. Find out what new and exciting postsecondary education initiatives are available nationwide. And, learn how to include postsecondary education planning in transition planning for students with intellectual disabilities. A short DVD on postsecondary education in action will be shown. This will be an interactive session with ample time to ask questions and to interact with one another.



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### 14a Integración Escolar y Programación Educativa – Part 1

**Emilio Ruiz Rodríguez**, Psicólogo y Asesor Psicopedagógico de la Fundación Síndrome de Down de Cantabria. Director del Área de Educación-Psicología del Canal Down21, España

Se realizará un estudio de las modalidades de integración escolar que pueden utilizarse con alumnos con síndrome de Down, defendiendo la modalidad de integración con apoyos como la más adecuada. Repaso de los principios básicos que han de regir la programación educativa de los alumnos con síndrome de Down, teniendo en cuenta las peculiaridades de su proceso de aprendizaje.

### 14b Integración Escolar y Programación Educativa – Part 2

#### WORKSHOPS: JULY 6, 10:30 AM

#### 16 How You Can Help Your Child or Young Adult Live a Healthier Life

**Suzanne Faber**, MPH, Health and Nutrition Coach, mother of a son with DS, Monument, CO

There is more to life than medicine and surgery. Healthy living is not as hard as you think. Why should you care about what your children and young adults eat? What does “whole food nutrition” really mean? How can you encourage healthier eating and exercise habits? How can I learn the “NO - NO’s” and recipes for gluten free eating, snacks and meal plans? Attend this fun, interactive workshop to find the answers to these questions and more.

### 17 The Importance of Optimal Sensory Functions with Focus on Vision and Hearing in Persons with DS

**Siegfried Pueschel**, MD, PhD, JD, MPH, Professor of Pediatrics, Brown University, The Alpert Medical School, father of a son with DS, Providence, RI

This presentation will highlight the significance of the sensory functions in persons with DS. Initially the external features of the eye and the various ocular disorders observed in many individuals with DS will be described. Then the otology concerns will be discussed, in particular, changes of the eardrum, infections, fluid accumulation and anomalies of the small bones in the middle ear that often will cause conductive hearing loss. Also, several of the inner ear problems that may lead to sensory-neural hearing impairment will be highlighted. Particular emphasis will be on visual and auditory processing and the educational implications in children with DS. Our detailed studies indicate that our children will benefit from teaching strategies that take into account the strength of visual processing modalities in persons with DS.

### 18 Early Speech and Language Skills: Birth to Preschool

**Libby Kumin**, PhD, CCC-SLP, Professor of Speech-Language Pathology and Author, Loyola University, Baltimore, MD

The session will focus on the early development of communication skills in young children with DS. What are the differences between communication, language and speech? What prepares your child to speak? Dr. Kumin will describe, as well as provide examples and home activities for early communication, language and pre-speech skills that children need to master. 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. The information will span the period from birth to preschool. If you have your baby/young child with you, please sit up front so that Dr. Kumin can work with them to demonstrate techniques to promote speech and language.



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## 19 Video Modeling: An Engaging and Effective Means to Teach Children with DS

**Susan Ellis**, BSAC, Co-founder, Director of Operations, The TV Teacher, LLC, mother of two children with special needs, Marietta, GA

This presentation will explain why video modeling, a research and evidence-based practice, works so well with children with DS. You will learn how to create your own teaching tools (self help, social, academic, etc.) for home or school using simple and fun techniques. Through demonstrations and discussions, the basics (i.e. who, what, and how) of creating successful video modeling tools will be shared.

## 20 Special Needs Apps: Getting Started, How-To's and Success Stories

**Cristen Reat**, Co-Founder of SNApps4Kids and mother of a son with DS and Tricia Brinks, Educator & Member of SNApps4Kids, both from Houston, TX

This presentation will focus on creative and practical ways to use the iPad, iPod Touch and iPhone at home, in activities of daily living, and in an educational environment. Learn how to use Google images, create schedules, and support learning and self-help skills in people with DS. We will offer an overview of how to use the SNApps4Kids website as a tool to explore the numerous apps on the market and share success stories. Participants will come away with a recommended list of apps, a plan for getting started and an understanding of the benefits and limits of a direct interface device. SNApps4Kids is a community of parents, therapists, doctors and teachers who share information on how we are using the iPad, iPhone, iPod Touch and Android devices with children who have special needs.

## 21a Maximizing Academic Potential: Treating Medical & Behavioral Conditions Associated with DS – Part 1

**George T. Capone**, MD, Director, DS Clinic, Kennedy Krieger Institute, NDSC Board Member, Baltimore, MD

By any definition DS is a complex condition. Individually, children with DS can differ markedly from one another in their medical, developmental and behavioral attributes and academic skills. Understanding any particular child's strengths and challenges is critical to successful learning and inclusion both in the classroom and across community settings. Some children have especially complex needs because of the particular constellation of medical-developmental-behavioral challenges they face. Certain aspects of brain developmental function and common behavioral characteristics of young children with DS will be reviewed. Strategies for recognizing, prioritizing and managing children with complex medical-developmental-behavioral needs in the home and school setting will be discussed.

## 21b Maximizing Academic Potential: Treating Medical & Behavioral Conditions Associated with DS – Part 2

## 22 Teaching Strategies for Supporting Healthy Sexuality

**Terri Couwenhoven**, MS, AASECT certified Sex Educator, Sexuality Consultant, TC Services, mother of a daughter with DS, Port Washington, WI

This workshop is designed to help parents understand the critical roles they play in helping their children, teens, and adults become sexually healthy adults. An emphasis will be placed on teaching strategies (how to teach) and key foundational concepts (what to teach) that support healthy sexuality. Practical ideas for teaching and resources for all ages will be shared.

## 23 Great Jobs Through Supported Employment

**Diane Prindle**, Briggs & Associates, Atlanta, GA

Briggs & Associates will share job descriptions that have been developed in various industries, such as hospitals, government agencies, corporate & law offices, attractions, and warehouse & distribution. Discussion will revolve around how these jobs can be



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developed through supported employment programs in your community. This collective source of information is invaluable to all families and service providers.

## 25 La familia y el manejo de los comportamientos problemáticos

**Elina R. Manghi**, PsyD, LMFT, Faculty, Adler School of Professional Psychology, Chicago, IL

A través de este taller se presentarán las guías completas de buena práctica familiar para el tratamiento de los problemas de comportamiento en niños con síndrome de Down. Los participantes tendrán la oportunidad de aprender intervenciones para: mejorar la comunicación y el desarrollo social; y manejar las conductas problemáticas.

## WORKSHOPS: JULY 6, 3:30 PM

### 28 My Kid has More Chromosomes Than Yours! Positive Outcomes in Parenting a Child with DS

**Briana S. Nelson Goff**, PhD, Professor, Family Studies and Human Services, Kansas State University, mother of a son with DS, Manhattan, KS and **Nicole Springer**, PhD, Department of Applied and Professional Studies, Texas Tech University, mother of a daughter with DS

This workshop will describe results from a national study with parents that explores the journey to resilience and hope experienced by families with a child with DS. The workshop will describe key resilience factors in families who have successfully navigated this life transition and provide important information and resources for families who may be beginning their journey. Because the mainstream publications in this area often are not empirically-based and many of the books provided to new parents are medically-based and difficult to comprehend while

coping with the news of their child's diagnosis, this workshop will specifically address evidence of the positive outcomes parents experience. We will specifically include participant discussion of relevant resources that have benefitted parents in their journey, and will assist new parents in the early stages of this journey to identify and advocate for their needs as well as their child's.

### 29a Potential Use of Computer Skills for Employment of Adults with DS – Part 1

**Libby Kumin**, PhD, CCC-SLP, Professor of Speech-Language Pathology and Author, Loyola University, Baltimore, MD

Do your teen and adult children email their friends? Do they search the web and go on to fan websites for their favorite singers? Computer skills are potential job skills. Dr. Kumin will talk about current research that is identifying strong computer skills in young adults with DS. How do we apply the research findings to help all people learn these skills? How do we use the knowledge to develop IEP and transition plans that can include both computer skills and communication skills essential in the job market? Involving school and employment counselors, and developing internships and volunteer opportunities as a bridge to employment will be discussed. A checklist of computer skills for employment will be included.

### 29b Potential Use of Computer Skills for Employment of Adults with DS – Part 2

### 30a The Surprising Role We All Can Have in Shaping the Future of DS – Part 1

**Mark W. Leach**, JD, Down Syndrome of Louisville, father of a daughter with DS, Louisville, KY

As a parent, family member, educator, professional, or someone interested in Down syndrome, we each can have a role in shaping the future of DS. Prenatal testing advances are only continuing to progress, but with surprising results. While studies have wondered whether DS would disappear, other studies have reported the number of births remaining the same, and even rising in the United States. This presentation will explain how both of these impacts are possible. It will also share how we each can have a role to play in responding to the needs of expectant mothers and the medical professionals that serve them. Because if we do not respond to this need, who will?



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Come and learn how you can have a role in shaping the future of DS.

### **30b The Surprising Role We All Can Have in Shaping the Future of DS – Part 2**

#### **31 Not Just Baby Teeth! Oral Health Care for Individuals with DS**

**LaQuia A. Walker**, DDS, MPH, Clinical Assistant Professor of Pediatric Dentistry, Indiana University School of Dentistry/Riley Hospital for Children, Indianapolis, IN

Oral health care in children for any parent can be challenging, and oral health care for children with special health care needs can provide its own set of challenges. However, these can easily be conquered by any pediatric dentist. The audience will be advised as to the various dental characteristics that can be present in children born with DS, what is necessary to maintain optimal oral health care, long term outcomes, and why children with DS should be seen by a pediatric dentist.

#### **32a Gross Motor Development in Children with DS: Birth to Walking – Part 1**

**Patricia C. Winders**, PT, Senior Physical Therapist, Sie Center for Down Syndrome, The Children's Hospital, Aurora, CO

This presentation will provide an overview of gross motor development in children with DS. It will include the goal of physical therapy, the factors influencing gross motor development, critical times for intervention, and treatment strategies. The focus will be on the gross motor skills learned during the period of birth to walking.

#### **32b Gross Motor Development in Children with DS: Birth to Walking – Part 2**

### **33 Keeping Children and Adolescents with DS Healthy: All the Medical Updates that Parents Need to Know**

**Siegfried Pueschel**, M.D., Ph.D., J.D., M.P.H., Professor of Pediatrics, Brown University Medical School, father of a son with DS, Providence, RI

Many persons with DS may have difficulties freeing themselves from the role of the child and they may not be fully equipped yet to assume the responsibility of a mature adult. Frequently, people with DS have most of the physical attributes of typical adolescents, but they often lack the cognitive and behavioral capabilities to cope with the demands of the environment and their own desire for independence. This workshop will address the psychological challenges of transition from childhood to adulthood and present strategies to improve the process.

#### **34a Sing, Play and Learn! Handwriting Development for Early Learning Success – Part 1**

**Diane Eldridge**, RN, COTA, National Presenter for Handwriting Without Tears, Manassas, VA

This interactive session offers creative letter play activities to develop skills that lay the foundation for pre-writing skills and readiness. Learn about emergent forms of writing, including drawing shapes, coloring and creating letters and numbers using wooden pieces, dough and a slate board. Meet Mat Man, who teaches drawing skills, body awareness and number skills. This Handwriting Without Tears session includes music, movement and manipulatives to develop emergent handwriting skills for children who have diverse learning styles and abilities. Come prepared to PLAY!

#### **34b Sing, Play and Learn! Handwriting Development for Early Learning Success – Part 2**

#### **36 Count on It: Early Math Instruction Can Benefit Your Child**

**Dana Halle**, JD, Co-founder and Executive Director, Down Syndrome Foundation of Orange County/DownsEd USA, mother of a son with DS, Newport Beach, CA



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Math matters. Every day students face choices and routines that involve math concepts: waking up and getting to school on time, following a schedule or playing a game. Math instruction can be powerful and effective when integrated into daily activities from an early age. This presentation describes the importance of early math instruction, explains basic math concepts, provides effective math-focused activities for home or school and includes video demonstrations.

### **37a Planning for your Child's Future as an Adult in the Community – Part 1**

**Hal Wright**, CFP, Financial Planner, Colorado Financial Partners, LLC, father of a daughter with DS, Greenwood Village, CO

The purpose of comprehensive special needs planning — life, resource, financial and legal — is to help an adult with a disability take their rightful place in the community. Planning should be person-centered. It must consider the individual's needs and capabilities, but it should be guided by his or her hopes for their own future. For many of our children, living independently in the community with some support is possible with adequate planning and resources. This workshop will present practical guidance to help you plan for your child's future as an adult in the community.

### **37b Planning for your Child's Future as an Adult in the Community – Part 2**

### **38 Start a "Cool Club" Social Club for Teens and Adults**

**Sandra McElwee**, mother of a son with DS, Rancho Santa Margarita, CA

Every teen and adult with DS deserves the same rich social life everybody else enjoys. Learn how to facilitate the fun by partnering with other parents and caregivers to create a social club that has one activity

EVERY weekend! You will learn how Cool Club started and be equipped with the information and tools to start a club for your teen or adult.

### **39a La Inclusión Del Alumnado Con Síndrome De Down En Las Escuelas. Claves Para El Éxito – Part 1**

**Emilio Ruiz Rodríguez**, Psicólogo y Asesor Psicopedagógico de la Fundación Síndrome de Down de Cantabria. Director del Área de Educación-Psicología del Canal Down21, España

Quando llega un alumno con síndrome de Down a la escuela, el profesorado se encuentra con que no sabe a ciencia cierta qué hacer, por dónde empezar, ni cómo abordar la intervención. En este taller se pretende proporcionar algunas claves para que un maestro que quiera integrar a un niño o a una niña con síndrome de Down en su clase tenga, al menos, unas mínimas posibilidades de éxito y, sobre todo y especialmente, que no se quemé en el intento.

### **39b La Inclusión Del Alumnado Con Síndrome De Down En Las Escuelas. Claves Para El Éxito – Part 2**

## **WORKSHOPS: JULY 7, 8:30 AM**

### **41a The Power of Empowerment – Part 1**

**Nancy Gianni**, Founder and CEO, GiGi's Playhouse, mother of a daughter with DS and Jenni Von Tobel, Executive Director, GiGi's Playhouse, Hoffman Estates, IL

This workshop will discuss how raising expectations of individuals with DS can empower parents, individuals with DS and the local community. Together, we will learn how to turn belief of your child's potential into action in your home and community. The end result is a home, school system, and community that upholds the high expectations you have for your child/adult. You will come away with a variety of tools and resources that you can implement and utilize in your local community.

### **41b The Power of Empowerment – Part 2**



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## 42 Introduction to D.A.D.S.: What it is and Why it Started

**Joe Meares**, John Goodrich, Ted Scofield and Jeff Huffman, D.A.D.S. National, all fathers of children with DS

D.A.D.S. started in 2002 with eight fathers who needed to fill a void. Find out how this void was filled for many fathers, how D.A.D.S. works within your local parent affiliate group and how to get connected with other fathers from around the country for support, fellowship and action.

## 43 DS Medical Clinic Experience: Perspective on Current Diagnostic Challenges

**Fran Hickey**, MD, Director, Anna and John J Sie Center for Down Syndrome, Denver Children's Hospital, father of a son with DS, Aurora, CO

This workshop will discuss why the coordination of care can improve the health of children with DS and how this happens at DS Clinics around the world. Attendees will be provided an up-to-date assessment of the DS Medical Guidelines from a best practice and evidence-based perspective, and will participate in discussions on recent findings that the care of children with DS indicate a need for more in depth evaluation in the areas of sleep apnea, pulmonary hypertension, feeding problems, immune deficits and pulmonary issues. Current controversies surrounding medical and prenatal issues will also be presented for discussion.

## 44a Gross Motor Development in Children with DS: Post Walking – Part 1

**Patricia C. Winders**, PT, Senior Physical Therapist, Sie Center for Down Syndrome, The Children's Hospital, Aurora, CO

This workshop will discuss the role of physical therapy in children with DS. It will include the goal of physical therapy, critical times for intervention, and the development of gross motor skills and treatment

strategies. Post-walking skills and foot management will be focused on as well as examples of dance and sports programs that we have implemented in Denver will also be discussed.

## 44b Gross Motor Development in Children with DS: Post Walking – Part 2

## 45 Feeding Issues in the Birth – 5 Population: Implications for Future Oral Motor and Speech Development

**Renee Roy Hill**, MS, CCC-SLP, TalkTools Therapy/ Lecturer and Crossroads Therapy Clinic, New Braunfels, TX

This course is designed to address early feeding skills in the Birth-5 population. Early feeding skills are critical in the development of later oral motor skills, mature feeding skills and speech clarity. Participants will learn what to look for in "good" feeding skills rather than simply "safe and adequate" feeding. Addressing these skills early is critical and will reduce later "bad habits" that evolve around spoon feeding, cup drinking, straw drinking, chewing and swallowing. Parents will learn techniques to facilitate lip closure, tongue retraction tongue lateralization and jaw grading for chewing. Families will also become aware of how medical, environmental and sensory experiences can alter feeding outcomes. Videos of both positive and negative feeding experiences will be shown as part of the learning process.

## 46 Teaching Children with DS to Read

**Dana Halle**, JD, Co-founder and Executive Director, Down Syndrome Foundation of Orange County/DownsEd USA, mother of a son with DS, Newport Beach, CA

The session will provide participants with evidence-based methods, activities and tools for effective home or classroom literacy instruction. Intended for children 2 through 5 years (or any child who is not yet reading), topics include vocabulary development, sight word acquisition, sentence building, basic comprehension and personalized materials. Illustrated with video examples from students in The Learning Program™ and with ample time for questions, this session aims to empower parents and professionals to build better readers. Instructional guides and sample materials will be provided.



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## **47a Positive Strategies for Enhancing Communication Development – Part 1**

**Stephen Camarata**, PhD and **Mark Wolery**, PhD, John F. Kennedy Center on Development and Disabilities, Vanderbilt University School of Medicine, Nashville, TN

People with DS often develop speech and language skills according to their own unique set of strengths and weaknesses. This requires individualized strategies and a positive partnership between the self advocate, parents, clinicians and teachers to facilitate communication development. The purpose of this workshop will be to present, in family friendly terms, methods for enhancing communication development in people with DS. Strategies for team building among professionals and families will also be discussed.

## **47b Positive Strategies for Enhancing Communication Development – Part 2**

## **48a Broader Look at Education Over the Last 30 Years – Part 1**

**Frank Buckley**, CEO, Down Syndrome Education International/USA, United Kingdom, brother of a sister with DS

Education for young people with DS has been transformed in some countries over the past 40 years — yet, it is far from perfect. This workshop will look at how education and thinking about the learning needs of children with DS has changed, the obstacles to effective education today and how we can improve educational outcomes in the future.

## **48b Broader Look at Education Over the Last 30 Years – Part 2**

## **49 Implementing Adult Literacy in Meaningful and Creative Ways**

**Tom Fish**, PhD, Founder, Next Chapter Book Club, Columbus, OH

This workshop will explore various approaches that can be used to promote adult literacy and community inclusion for people with DS. It will also provide a comprehensive overview of the Next Chapter Book Club Model.

## **50a Perspectives on Sleep and Mental Health Function in Adolescents & Adults – Part 1**

**George T. Capone**, MD, Director, DS Clinic, Kennedy Krieger Institute, NDSC Board Member, Baltimore, MD

While there is still much to learn about the neurobiology of DS, several lines of research suggest that brain function is more vulnerable to impairment in persons with this condition. Stressful psychological and social circumstances are also more likely to trigger mental health changes in vulnerable individuals. Obstructive sleep apnea may mimic or complicate symptoms of mental health condition. Pharmacologic therapies are being used for a variety of neurobehavioral conditions including: Depression, Anxiety, psychotic-like features and Obsessive-Compulsive Disorders. This workshop will explain that together with behavior management, counseling, and treatment of sleep disorders, medications may be helpful in reducing specific symptoms and maladaptive behaviors that can interfere with optimal function and quality of life.

## **50b Perspectives on Sleep and Mental Health Function in Adolescents & Adults – Part 2**

## **51 Transitions: The Roles of Siblings in the Transition out of the Home for Adults with DS**

**Michael Gibbons**, PhD, Visiting Assistant Professor, Department of Sociology, Gettysburg College, Gettysburg, PA

Dr. Michael Gibbons will discuss the findings of a study done in collaboration with NDSC called “Transitions” which looked at how families of adults with DS approach moving out of the family home. Early findings suggest that many parents are wary of the group home



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options they perceive to be available. Parental concerns focus on trust, control, and engagement. The report will formalize an understanding of the parents' experience regarding this transition, or lack thereof and communicate the options families do have, as well as identify their concerns and unmet needs.

### **52 Enseñanza Académica Básica para Estudiantes con Síndrome de Down y Autismo**

**Olga B. Vasquez-Silva**, Executive Director, One for Autism Academy, Laredo, TX

En esta sesión se conocerá la enseñanza de habilidades académicas básicas para los niños con síndrome de Down y diagnóstico de autismo. Se va a aprender sobre programas de principiantes, imitación, habilidades sociales y académicas.

### **WORKSHOPS: JULY 7, 12:00 PM**

#### **54 Adopting a Child with DS**

**Stephanie Thompson**, Assistant Director, National Down Syndrome Adoption Network, Cincinnati, OH, mother of a son with DS

This workshop will review the history of the National Down Syndrome Adoption Network, from its formation in 1982. A review of the process involved in adopting a child with DS, as well as the role that family and support groups can play in ensuring that every child, born with DS, has the opportunity to grow up in a loving family!

#### **56 Becoming D.A.D.S.: Making it Work**

**Joe Meares, John Goodrich, Ted Scofield and Jeff Huffman**, D.A.D.S. National, all fathers of a children with DS

This workshop is specifically for fathers who are already involved in a

local D.A.D.S. chapter. We will hear successes and challenges from D.A.D.S. groups and discuss strategies that are proven to add quality programming content, build recruitment and build the connection with your family support group. D.A.D.S. National will share examples of implementing the foundational pillars of D.A.D.S., support, fellowship and action. If you are a member of a D.A.D.S. group or especially if you are a leader — this is a can't miss workshop.

#### **57 Reaching for the STARS — Speech Therapy and Research Working Together**

**Jennifer Meyers Bekins**, MS, CCC-SLP, The Jane and Richard Thomas Center for Down Syndrome at Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Do you ever wonder, "Why do some individuals with DS have clear speech and others don't?" or "What can I do to help my child talk?" This course will take an in-depth look at the types of speech disorders that exist among children with DS, discuss the importance of evidence-based clinical treatment, and tackle common questions about using sign language, oral-motor therapy, and assistive technology. Participants will receive practical suggestions to use at home including tools and activities.

#### **58 Get a Grip on Printing with Handwriting Without Tears**

**Diane Eldridge**, RN, COTA, National Presenter for Handwriting Without Tears, Manassas, VA

Handwriting fluency is an essential component of early learning. Attendees will learn engaging instructional strategies to provide children with diverse learning styles and abilities to print legibly. This session introduces the Handwriting Without Tears program and its teaching techniques that are play-based using music, movement and multisensory activities. The creative strategies are developmentally appropriate and promote good habits to teach pencil grasp, letter/number formation, letter size, and spacing and sentence skills.

#### **59 Beyond Early Number Concepts: Creating a Math Plan & Introducing Time & Money**

**Dana Halle**, JD, Co-founder and Executive Director, Down



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Syndrome Foundation of Orange County/DownsEd USA, mother of a son with DS, Newport Beach, CA

Understanding early number concepts can provide a solid foundation for upper level math skills, but there are so many additional concepts to master for independence. By developing a math plan for your student, you can keep focused and track progress. This session focuses on the components of a basic math plan, successful support for teaching addition, subtraction, time and money and resources to help with instruction.

### 60 Inclusion in Private Schools: A Model for Success

**Mandi Ashley**, Director, Heart to Heart Program, Stephen Camarata, PhD, Professor, Vanderbilt University, **Chris Price**, Franklin Road Academy and **Glenn Funk**, Board Member, Franklin Road Academy and father of a son with DS, Nashville, TN

This session will provide a model for successfully including children with DS in a private school setting. This model, known as the Heart to Heart Program, furthers the child with DS's academic potential and develops the character of their typical peers. Hear from both administrators and parents how this model was created, funded and carried out.

### 61 Self Advocacy Through the Voices of Canadians

**Kirk Crowther**, Executive Director, Canadian Down Syndrome Society

This workshop will demonstrate how an organization can effectively include the voices of self advocates. The Canadian Down Syndrome Society Voices at the Table Advocacy (VATTA) has demonstrated how a group of 12 self advocates (adults with DS) can affect supportive changes to an organization and create new visions with a focus on personal perspectives. The role advocates play in directing the work of an agency or organization is identified. The VATTA committee has demonstrated strategies for self advocates and organizations that want to

include people with DS in their work.

### 62 How To Prepare for Independent Living

**Meredith Martin**, Self advocate, Neligh, NE and Lee Jones, Self advocate, Kansas City, MO

Whether your self advocate has just started crawling or just gotten their driver's license, it is never too early to start planning for the possibility of them living in their own place. This workshop will provide practical information on key skills to be learned, living alternatives, criteria for selecting a first place and the joys of success. This workshop is not about theories; it is about the real world and is being presented by two experts with over sixty-five years of daily experience with DS and almost twenty years of daily experience of living independently. You will leave the workshop with a check list and ideas on how to get started with preparing for independent living when you get home. The speakers will be joined by their support staff (also called parents) for a questions and answers period at the end of the presentation.

### 64 Intercambio Latino

**Linda Mora**, Coordinadora a de Apoyo a Grupos Minoritarios, NDSC, Atlanta, GA

Padres y profesionistas pertenecientes a diferentes asociaciones/organizaciones de síndrome de Down de Estados Unidos y los países asistentes de Latino América se reúnen para conocer el trabajo realizado por cada uno para intercambiar información, programas, logros, retos y sueños. Excelente oportunidad para establecer una red de contactos con las diferentes personas/organizaciones sobre síndrome de Down.



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