CO-OCCURRING DOWN SYNDROME AND AUTISM SPECTRUM DISORDERS

The NDSC cares about serving the needs of all families, including those with loved ones with co-occurring autism (DS-ASD), or autism-like tendencies. As a result the NDSC is collaborating with the Down Syndrome-Autism Connection, a nonprofit that serves this population specifically, to offer a specially-designed DS-ASD track at the Convention. Perhaps you have a loved one diagnosed with co-occurring DS-ASD, or you have wondered if your child may have “more than DS” due to behaviors or developmental issues, or perhaps you are a professional who works with individuals who seem to fit this profile...if so, then this track is for you!

The Down Syndrome-Autism Connection and NDSC together have developed this track, identifying experts in the field to speak on a variety of topics. In addition, professionals from the Connection will be on-site during each workshop to assist families and professionals with questions and concerns. Their warm, friendly staff has extensive training and personal experience and will be able to provide guidance, support and resources so you don’t have to feel alone on this journey. Check out the learning opportunities we have secured below:

CONNECTIONS RECEPTION - THURSDAY, JUNE 27, 7:30 - 9:00 PM

You Are Not Alone...When Your Loved One Has “More than DS”
This session will be facilitated by Charlotte Gray, Executive Director, and Jeanne Wheeler Doherty, Board President, of the Down Syndrome-Autism Connection. Both understand the joys AND challenges of raising a child with this complex, co-occurring condition.

It can be tremendously difficult and heartbreaking to learn that your child may be exhibiting some red flags for a second major diagnosis – Autism. This session is designed for parents who have a child with DS-ASD, or for those who suspect that their loved one with DS may have autism-like tendencies and behavioral challenges. The session is intended to give voice to the complexities of loving and caring for a person with this co-occurrence, as well as to foster a community of belonging for all on the DS-ASD journey.

PRE-CONFERENCE SESSION - FRIDAY, JUNE 28, 8:00 AM - 12:00 PM (separate registration required)

DS along with Autism Spectrum Disorder: Recognizing the Signs, Understanding the Diagnostic Process, and Exploring Intervention Approaches

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

Approximately 20% of children with DS meet criteria for a comorbid autism spectrum disorder (ASD). However, less is known about the learning and behavioral challenges and effective intervention approaches for this group. This preconference 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 comorbid 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 comorbid ASD.

WORKSHOP OFFERINGS - FRIDAY, JUNE 28 - SUNDAY, JUNE 30

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.

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*

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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.

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.
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.

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.