DS-ASD 101: Understanding the BASICS of co-occurring Down syndrome and Autism Spectrum Disorder

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**DS-ASD 101**

- The Down Syndrome-Autism Connection- Who we are:
  - **Our Mission:**
    - Provide education and support to individuals with DS-ASD
  - **Our Goal:**
    - Ensure that families, teachers and healthcare providers receive the education and support they need
  - **Time line:**
    - Founded in 2007
    - 2011 became non-profit – only one dedicated solely to DS-ASD in US
The Down Syndrome-Autism Connection - Who we are (cont):

- **Resources and Programs:**
  - Attend annual conventions with NDSC, MDSC and other DS conferences throughout the US
  - Referrals through DS clinics and MDSC
  - Facebook public page and support page
    - Down Syndrome Autism Connection Support
  - Quarterly E-newsletter
  - Monthly on-line chats
  - Webinars
  - Conference call facilitated sharing sessions
  - “Get Connected” welcome kits

- **Collaborations:**
  - Massachusetts Down Syndrome Congress
  - National Down Syndrome Congress
  - National Down Syndrome Society
  - DS clinics in Boston Children’s Hospital, Mass General Hospital, and UMASS Memorial Medical Center
DS-ASD 101

• Help us get to know you......

• How many......
  ◦ Parents/family members have a child with Down syndrome?
  ◦ Have a child ages:
    • 3-12
    • 13-18
    • Over 18
  ◦ Educators with a student with DS-ASD?
  ◦ Healthcare providers

DS-ASD 101

• Objectives:
  ◦ Prevalence with DS and ASD and what we know
  ◦ Diagnostic criteria for ASD
  ◦ History of DS-ASD and does ASD look different in a person with DS?
  ◦ Recent findings of DS-ASD and typical signs through the lifespan
  ◦ General and social developmental comparison between a person with DS and a person with DS-ASD
  ◦ Additional DS-ASD behaviors to pay attention to
  ◦ Journey with Jacob
Objectives (cont.):
- Breakdown of different behaviors (videos)
- Evaluations and Diagnosis:
  - Why it’s important
  - Where to get a diagnosis
  - Obstacles in getting an ASD diagnosis
- Treatment Recommendations
- What you can do as a caretaker

A Dad’s Perspective:
- Making a choice with what has been given to us
- Statistics on parenting a child with special needs and what it is that we need
- How we keep moving forward by choosing joy!
Prevalence today

- Down syndrome: 1 in 700 live births (per Center for Disease Control)
- ASD: 1 in 59 children and 1 in 37 boys and 1 in 151 girls (per Autism Speaks as of April 26, 2018)
- Current research indicates that about 10% of children with Autism are also identified as having Down syndrome (per CDC - Autism Spectrum Disorder Data & Statistics)
- Approximately 18% of children with Down syndrome met the criteria for Autism Spectrum Disorder (DiGuiseppi 2011)
  - The rate is 30 X greater than the general population (DiGuiseppi 2011)

Down syndrome – what we know

- We already know a lot about Down syndrome
- Can be very social
- Can be quite engaged in the community
- Can be goal oriented, high achievers
- Can live independently
- Can work, volunteer, and vote

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What is Autism Spectrum Disorder?

- Refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences.
- There is not one autism but many types, caused by different combinations of genetic and environmental influences.
- Autism’s most-obvious signs tend to appear between 2 and 3 years of age. In some cases, it can be diagnosed as early as 18 months.

More about Autism

- Before May, 2013, there were 5 separate categories of autism diagnosis.
- Today, according to the American Psychiatric Association's diagnostic manual, the DSM-5, there is just one: Autism Spectrum Disorder.
- No matter where a person may be on the spectrum, it’s all now considered autism.
Basic Diagnostic Criteria for ASD

- Persistent deficits in social communication and social interaction across multiple contexts and manifested by the following:
  - Deficits in social-emotional reciprocity
  - Deficits in nonverbal communicative behaviors
  - Deficits in developing, maintaining, and understanding relationships

Basic Diagnostic Criteria for ASD (cont)

- Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following:
  - Stereotyped or repetitive motor movements, use of objects, or speech
  - Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior

DSM-5 (APA, 2013)
Basic Diagnostic Criteria for ASD (cont)

- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment

DSM-5 (APA, 2013)

Additional Criteria

- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning
- These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay

DSM-5 (APA, 2013)
Additional Criteria (cont)

- Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

DSM-5 (APA, 2013)

History of DS-ASD

- 1979
  - Trisomy 21 most common rare condition associated with ASD (Wakabayashi)
- 1994
  - ASD was classified (First)
- 1997
  - Approx 75% of ASD persons also had cognitive impairment (Rapin)
- 1999
  - ASD in a person with DS estimated to be between 5% - 7% (Kent)
  - ASD appears to be higher in DS population
Does autism look different in a person with Down syndrome?

Yes and No!

No, because:
1. autism is considered a spectrum disorder -- meaning that it can look different in each person and there is a range of how each is impacted.

2. Each individual with Down syndrome and autism is unique as is the way their autism manifests.

Yes, because:

Individuals with DS-ASD have developmental differences as a result of having Down syndrome so they often experience greater challenges from autism than those without an additional developmental difference.
Does autism look different in a person with Down syndrome?

- In those with DS-ASD, the “spectrum” of symptoms can be somewhat narrower:
  - Many are nonverbal or have limited communication skills
  - Many have challenging and unsafe behaviors at home and school
  - Many are extremely rigid in their need for sameness

Some parents and professionals have observed that at times the "Down syndrome comes out," with glimpses of greater social and communicative intent.
Dr. Capone's recent findings (9/2016)

- General agreement about Autism:
  - A spectrum disorder
  - A developmental diagnosis
  - Can coexist with other conditions
  - A life-long condition for which there is no cure

- Most common “core features”:
  - Impairment in relating to people and social circumstances
  - Communication impairment
  - Repetitive body movements and/or persistent ritualistic behavior patterns

Dr. Capone’s recent findings (cont.)

- Children with DS-ASD often present in one of two ways:
- Group One (before 3 years old):
  - Repetitive motor behaviors
  - Fascination with and staring at lights, ceiling fans, or fingers
  - Episodic eye movements
  - Extreme food refusal
  - Unusual play with toys or other objects
  - Receptive language impairment
  - Little or no meaningful spoken language, gestures or signs
Dr. Capone’s recent findings (cont.)

- Group Two (3 yrs and older):
  - History of developmental regression
  - Hyper or hypo-activity, short attention, impulsivity and poor organization
  - Unusual vocalizations
  - Unusual sensory responsiveness
  - Difficulty with changes in routine or familiar surroundings
  - Extreme anxiety, fearfulness or agitation
  - Sleep disturbances
  - Disruptive behaviors
  - Self-injurious behaviors

Typical Signs of ASD in Teens and Adults with DS

- Significant lack of social response or relatedness with family or friends
- Lack of interest or ability to develop relationships with peers
- Antisocial, anxious, or fearful in the presence of people they don’t know
- Intensified stereotypic and repetitive motor behaviors
- Obsession or fascination with inanimate objects
- Lack of ability or interest in creative play

*When Down Syndrome and Autism Intersect*
Typical Signs of ASD in Teens and Adults with DS (cont.)

- Manipulation of objects in rigid ways
- Intensified sensitivity to certain types of sensory input
- Frequent tantrums and outbursts, as well as verbal or physical aggression
- Great difficulty in adjusting to transitions
- Dropping to the ground and refusing to move

*When Down Syndrome and Autism Intersect*
Comparison in General Development

- General Development in DS
  
  - Most domains develop in same order as typical kids, but at a slower pace
  - IQs usually range from 30-70, mean is 50
  - Most children make about 4-5 months of developmental progress per 12 months
  - Receptive language (not just vocabulary) is usually strongly associated with overall IQ

- General Development in DS-ASD
  
  - Development is uneven and “spotty”
  - IQs usually range from 20-60; mean is 40
  - Most children make about 1-2 months of developmental progress per 12 months
  - Receptive language is often impaired

Susan Hepburn, Ph.D. (4/22/15)

Comparison in Social Development

- Social Strengths in DS
  
  - Core relating (person-to-person, back and forth connections)
  - Imitation
  - Socialization is usually a relative strength in adaptive behavior in middle and high school
  - Can do pretty well with peers if supported

- Social Challenges in DS-ASD
  
  - Have difficulties in core social relating that cannot be explained by their overall developmental level
  - Have difficulty in becoming intentional communicators
  - Can be very challenging to motivate
  - Tend to really “get stuck” in routines/behavior patterns/chains

Susan Hepburn, Ph.D. (4/22/15)
Differences to ASD Alone

- May appear more social
- Stimming and repetitive behaviors are often times more frequent
- Areas more impacted:
  - Cognitive
  - Verbal
  - Self-help skills
- Is there a history of:
  - infantile spasms, regression, food aversion, sleep disturbances

Additional DS-ASD Behaviors to pay attention to:

- Happiest playing alone
- Does not return a smile automatically
- Eating problems—limited foods, textures, etc.
- Toileting challenges
Additional DS-ASD Behaviors to pay attention to (cont):

- Rarely includes other people in interests
- Hyperactivity or passiveness
- Organizing/lining up objects

- Inappropriate laughing or crying
- Strange attachment to objects
- Lack of awareness of danger
- Elopement (running away)
- Meltdowns (different than tantrums)
- Aggression toward others
More about behaviors

- Behavior has a purpose
- It’s communication!

My Journey with Jacob

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Activities of daily living

Hope
Breakdown of Behaviors

Let’s watch a few videos together then discuss which behaviors we were able to observe.

- Not all red flag behaviors mean autism
- Consider duration, severity, and how disruptive to life
- Behavior is communication

Stimming: Allow It or Stop It?

- Big question from parents
- Depends on the individual
- Depends on the behavior
  - Is it helping the person to self-regulate?
  - Is it a fixation? Is it detrimental?
  - Can you set aside time for this preferred behavior?
  - Can you allow it at specific times and locations?
  - Can you replace the behavior and/or redirect?
“Stimming” Behaviors

- Let’s take a look at some behaviors that can be considered self-stimulation and repetitive behaviors – or fondly known as “stimming”.

- Stimming can make our children “look” different.

- You’ll notice a few vocalizations and other “unusual” behaviors, as well.
I-Pad

Frog
Unusual Body Movements

- Body movements can look odd, but can be present for a variety of reasons:
  - Sensory
    - Self-stimulation
    - Tactile (sense of touch)
    - Vestibular (movement and balance)
    - Proprioceptive (input about body movement and position)
  - Show frustration
  - Sheer joy!
Need for Order/Routine

- It doesn’t need to make sense to you for it to be important to the person.
  - They know what they want and why
  - Very bright – autism can mask intelligence that’s “in there”
  - Multi-tasking skills and use of electronics can be impressive!

Blocks
Circles

Dancing
Anxiety

- Clinically significant anxiety occurs frequently among individuals with autism and is linked to increased psychosocial, familial, behavioral and academic impairment beyond the core autism symptoms when present.
- Behaviors can include:
  - Flapping
  - Rocking
  - Self-injury
  - Escaping the situation

Other Anxiety Provoking Challenges and Difficulties

- Vacations and unplanned travel
- Medical and dental appointments
- Unfamiliar environments
- Transitions in all areas
Apples

“It’s OK”
Positive Changes in Behavior in teens and adults

- Increase in maturity:
  - better understanding of social stories
  - ability to self regulate and tolerate different/challenging environments

- Improvement in Receptive Language:
  - ability to follow more complex directions – increased independence

- Increased participation in decision making and self-advocacy
Help Me

Blood Draw Success
Let’s Jam

Evaluation and Diagnosis

- Why?
  - Are there benefits
  - Weigh pros and cons
- How – what’s involved
  - Education dx
  - Medical dx
  - Multidisciplinary approach especially when extremely complex
- Where?
  - DS Clinic
  - Children’s hospital or developmental pediatrician
  - Neuropsychologist
Where to get evaluations

- The **Association of University Centers on Disabilities** (AUCD) may be a great place to start. ([http://www.aucd.org/directory/directory.cfm?program=UCEDD](http://www.aucd.org/directory/directory.cfm?program=UCEDD))

- If you'd like to search for Children's Hospitals in your area, consult the **Children's Hospital Association's directory**. ([https://www.childrenshospitals.org/](https://www.childrenshospitals.org/))

- Down syndrome specialty clinic database through ndss.org. ([http://www.ndss.org/Resources/Health-Care/Health-Care-Providers/](http://www.ndss.org/Resources/Health-Care/Health-Care-Providers/))

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Down syndrome specialty clinics

[Map of Down syndrome specialty clinics](http://www.ndss.org/Resources/Health-Care/Health-Care-Providers/)
Obstacles to getting an ASD Diagnosis

- Lack of Familiarity by families and professionals
  - Some will consider atypical development and behavior to be an expected part of Down syndrome

- Diagnostic Confusion
  - Individuals with DS are often very social; Individuals with autism are often socially impaired.

- Overshadowing and reliance on a single diagnostic label
  - Sometimes ASD is overlooked or considered inappropriate for a child with Down syndrome due to the presence of severe intellectual disability.

*Down Syndrome and Autistic Spectrum Disorder: A Look at What We Know, Disability Solutions, George T. Capone, MD, 1999*

Why Should We Care to Learn More About DS-ASD?

- Isolation
- Emotional needs – family
- Need for different interventions for behavior, learning, education
- Medical Issues
- Support
- Resources

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Treatment Recommendations

- Behavior management plan/frequency
  - Applied Behavior Analysis
  - Floortime
  - Feeding
  - Sensory
  - OT
- Establish a functional communication strategy
- Re-evaluating program structure (1:1)
- Nutrition/diet accommodations
- Medication

Hope for the future – What can I do?

- Open up your circle of support
- The more people that know your child, the better (friends, family, support staff from school, etc.)
- This will enable more independence for both you and your child
- Pursue a personal care attendant, AFC and respite hours from DDS
Hope for the future – What can I do?

- YOU MUST TAKE CARE OF YOURSELF!!
  - Set goals for yourself, your child and your family
  - Identify and acknowledge your feelings
  - Seek professional counseling when you need it
    - Connect with us (www.ds-asd-connection.org, facebook support page, monthly on-line chat)
  - Family and friends know you best
  - Doctors, therapists, and religious organizations can help address unanswered questions
  - Conferences, workshops, parent-to-parent connections
  - Attend to your own healthcare needs
  - Get enough rest, proper nutrition, and regular exercise
  - Take time off *without feeling guilty*
  - Change the way you view certain situations

A Dad’s Perspective
The Road Goes Ever On

The Good, The Bad and The ‘Ya’ Think?

- Statistics on parenting a child with special needs:
  - 80% divorce rate is an ‘Urban Myth’
  - No research is perfect
  - 2 Studies – Hartley et al. (2010)(2) and Freedman et al. (2011)(1) – ‘Ya’ Think?
  - Babies change everything!
What is it that we need?

- What men want
- What women want
- The challenges for men and how wives can help
- How to talk to one another
- Counseling
- Try finding time together

Keep Moving Forward
Choosing Joy

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Resources

- www.mdsc.org (MDSC)
- www.ndsc.org (NDSC)
- www.ndss.org (NDSS)
- www.autismspeaks.org (Autism Speaks)
- www.massgeneral.org/downsyndrome (Mass General DS Clinic)
- www.childrenshospital.org/downsyndrome (Boston Children’s DS Clinic)
- www.masshealth.gov (Masshealth)
- www.dds.gov (DDS)

Questions?
Thank you

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