

DS-ASD 101:

Understanding the BASICS of co-occurring Down syndrome and Autism Spectrum Disorder



Presented by:

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www.ds-asd.connection.org

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

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- 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

DS-ASD 101



- The Down Syndrome-Autism Connection- Who we are (cont):

- 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

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- 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

DS-ASD 101

- 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

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- 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!

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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 (DiGuseppi 2011)
 - The rate is 30 X greater than the general population (DiGuseppi 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.



Autism Speaks

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

DSM-5 (APA, 2013)

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.

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Does autism look different in a person with Down syndrome?

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.

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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

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Does autism look different in a person with Down syndrome?

Some parents and professionals have observed that at times the "Down syndrome comes out," with glimpses of greater social and communicative intent.



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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

Elmo



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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)

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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)

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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



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Additional DS-ASD Behaviors to pay attention to (cont):



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

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Additional DS-ASD Behaviors to pay attention to (cont):

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

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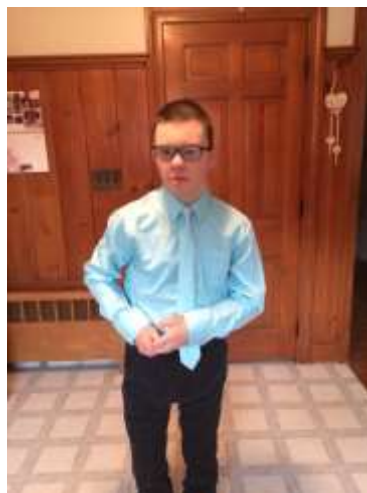
More about behaviors

- Behavior has a purpose
- It's communication!



When Down Syndrome and Autism Intersect

My Journey with Jacob



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Activities of daily living



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Hope



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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

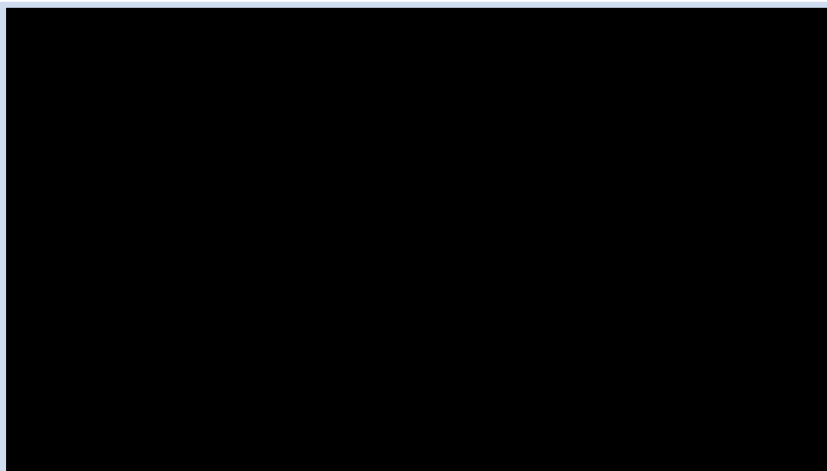
Stimming: Allow It or Stop It?

- 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.

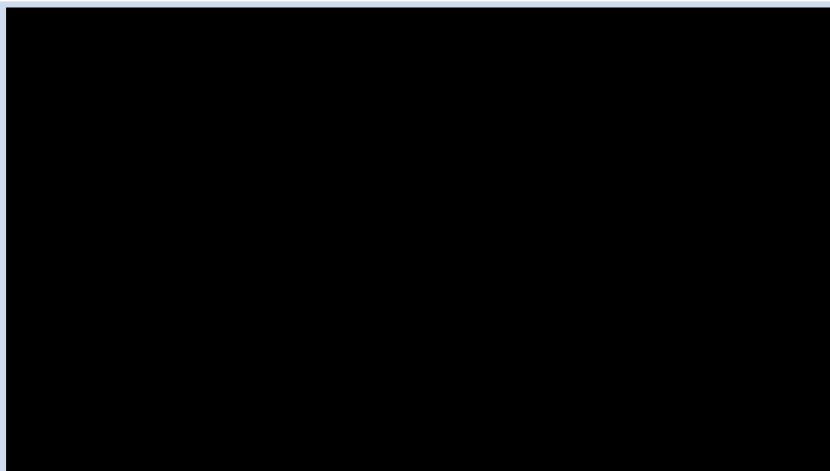
Chair



I-Pad



Frog



Dangly Things



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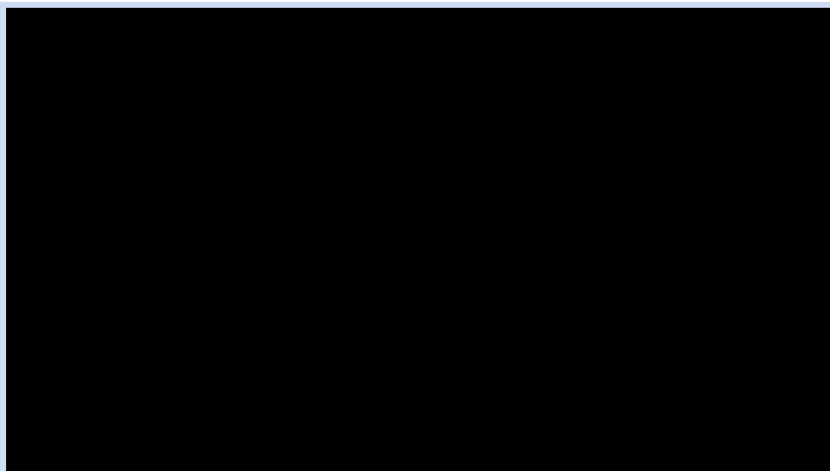
Unusual Body Movements

- 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!

Happy



Kitchen Spoon



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

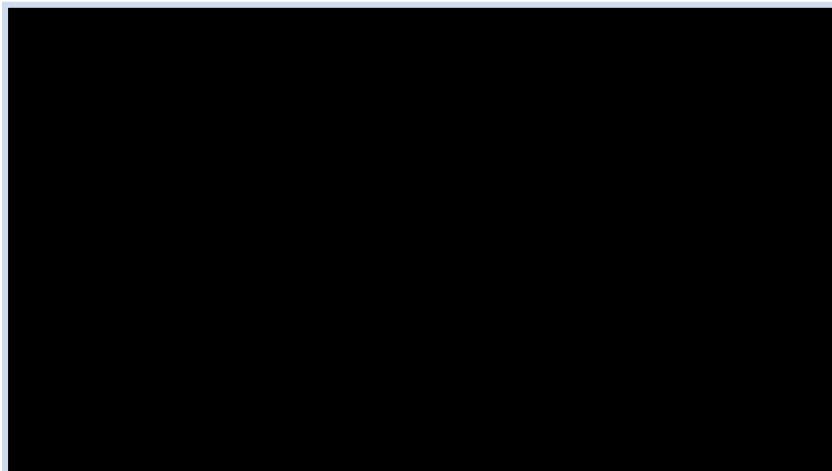


Wiggles

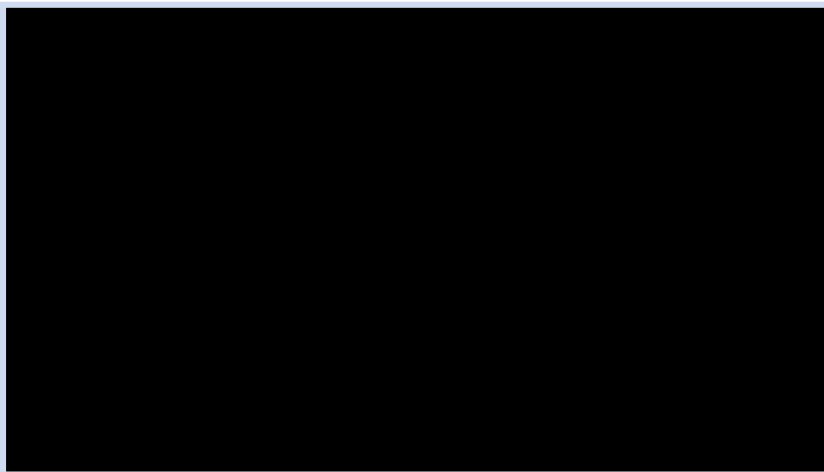


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Flip-flop

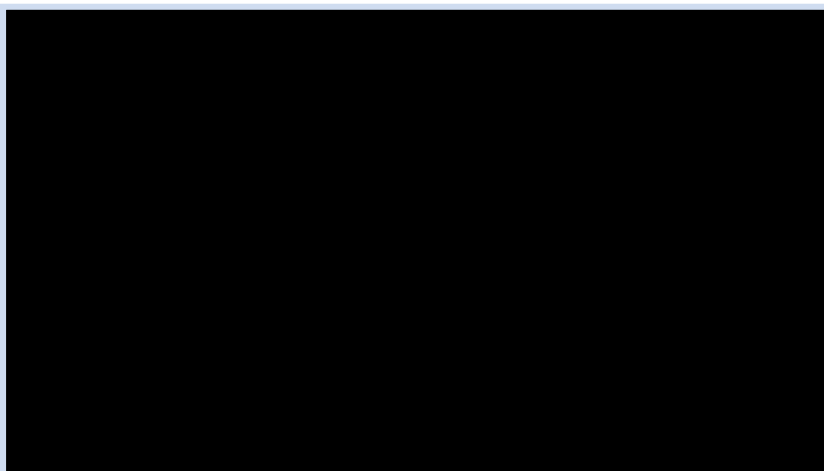


Circles



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Dancing



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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



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"It's OK"



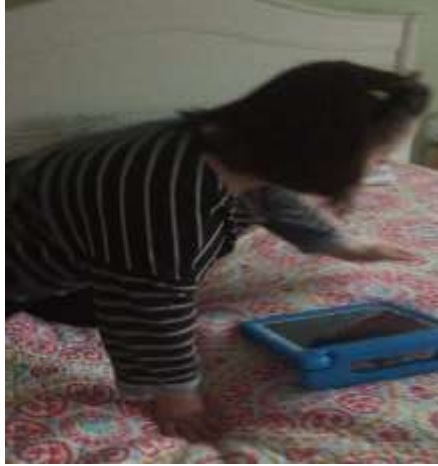
Hike



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



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Blood Draw Success



Let's Jam



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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](http://www.aucd.org/directory/directory.cfm?program=UCEDD) (AUCD) may be a great place to start. (<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](https://www.childrenshospitals.org/) directory. (<https://www.childrenshospitals.org/>)
- Down syndrome specialty clinic database through ndss.org. (<http://www.ndss.org/Resources/Health-Care/Health-Care-Providers/>)

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, face book 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



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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!



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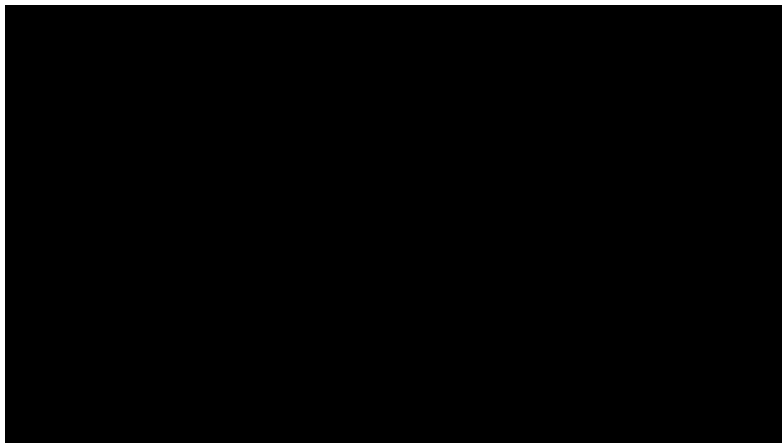
What is it that we need?



- 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

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Keep Moving Forward



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Choosing Joy

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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)

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Questions?



Thank you

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