

Is it Sensory or is it Behavior? Strategies to Support Individuals with Down Syndrome

July 23, 2023 - National Down Syndrome Congress Convention

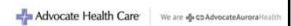
Katie Frank, PhD, OTR/L | Occupational Therapist
Abby Rowley, LCSW | Social Worker



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Please note:

- This presentation is intended for families, caregivers, health care professionals, and service providers of individuals with Down syndrome.
- The information in this presentation is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.
- We recommend that you bring specific questions about an individual with Down syndrome to their medical and/or therapy providers.



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Today's agenda

- Identify potential causes of behavior change.
- Determine how to assess whether it is a sensory need or a behavioral issue.
- Share practical behavioral and sensory strategies.



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Behavior



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What is behavior?

- Anything that an organism does involving an action and response to stimuli.
- That way in which an organism functions or operates.
- Everything we do is behavior!
- Occurs within the context of a situation, but also within the context of neurodevelopment.



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The important point is that difficult behaviors do not occur by accident, or because someone has a disability. Difficult behaviors are expressions of real and legitimate needs. All behavior, even if it is self-destructive, is "meaning-full".

David Pitonyak, PhD
Blacksburg, VA
Down Syndrome News



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Function	Behavior May Appear as...
Attention	Silliness, overly touchy, loud voice, risky/dangerous behaviors, inappropriate language, running away/hiding, feigning medical issue, Any behaviors that draw attention of others.
Access (items/activities/locations)	Taking things that don't belong to them, refusing to give up preferred items, refusing to leave preferred locations, online shopping
Escape/avoidance	Running away, hiding, putting head down, fainting/feigning medical issue, freezing, dropping to floor, ripping up paper, refusal
Sensory	Overly physical with others, lots of jumping/running/crashing, refusal to go into loud/bright areas

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Common characteristics that may impact behavior in DS

- The brain
- Self-talk
- The "groove"
- Visual memory
- Empathy radar

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Examples of behavior challenges in DS

- Change in self-talk
- Exhibiting obsessive-compulsive behaviors
- Stubbornness/oppositional behavior
- Becoming agitated or aggressive
- Regression of skills
- Impulsivity
- Self-stimulatory behaviors
- Throwing tantrums or having meltdowns
- Wandering off
- Difficulty following changes to routine
- Short attention span
- Anxiety/sadness
- Avoidance
- Poor boundaries

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What can cause problematic behavior?

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Causes of problematic behavior

- Health
 - Mental
 - Physical
- Sensory
- Social/Environmental

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Mental health causes

- Depression
- Anxiety
- OCD
- Down syndrome regression disorder (DSRD)
- Situational stressors
 - Grief / loss / trauma

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Physical health causes

- Sleep apnea
- Vitamin B12 deficiency
- Celiac disease or other GI issues
- Vision or hearing impairment
- Hypothyroidism
- Pain
- Seizures/neurological conditions
- Alzheimer's disease

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Sensory causes

- Problems with the ability to process information received through the senses (sight, sound, touch, taste, smell, muscles/ joints, balance) which **impact a person's ability to function in their daily life.**

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Social causes

- Managing relationships.
- Navigating situations at school or work.
- Adjusting to changes in routine.
- Life stressors or changes

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How do we address problematic behavior?

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Approach

Decide if the behavior change needs to be addressed.

- Does the behavior interfere with development and learning?
- Are the behaviors disruptive to the family/school/workplace?
- Is the behavior harmful to the child/adult or others?
- Is the behavior different from what might be typically displayed by someone of comparable developmental age?

What is the individual trying to communicate?

- Needs, desires, challenges

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Approach (cont.)

Talk to a health care provider.

- Address physical and/or mental health causes.
- Interaction between mental and physical health.
- Communication challenges.
- Seek guidance from other professionals.

Utilize other strategies.

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Strategies

Health

- Medicine / tests / procedures
- Exercise
- Healthy eating
- Getting better sleep

Non-medical / non-health

- Sensory
- Structure / routine
- Social supports

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Is it sensory or is it behavior?

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Sensory or behavior?

- It can be both.
- Sometimes the only way to tell depends on which interventions are working...either sensory or behavior management.
- Sensory input should NEVER be removed as part of a behavior plan. Input is not a reward either.
- An approach that utilizes both sensory input and behavior management techniques typically work best.

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Questions to ask...

1. Does the person's action disrupt your life by limiting the places you can go or the activities you do?
2. Does the action occur with everyone or just specific people or environments?
3. Does the person stop the action when given what's desired?

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Our Sensory System

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Our sensory system



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Our sensory system



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Sensory and behavior



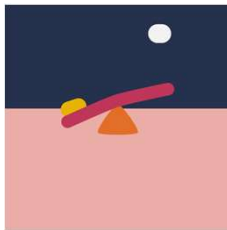
The kink can impact behavior.

We may see...

- verbal outbursts
- physical aggression
- slowing down
- shutting down

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There are 8 senses!

Far Sensory Systems

Touch
Sight
Smell
Sound
Taste

Near Sensory Systems

Vestibular
Proprioception
Interoception

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Common sensory deficits in DS

Tactile- not tolerating certain clothing types; not tolerating lotion on skin or brushing teeth; not tolerating water on face

Auditory- likes their music loud, but may not tolerate other loud sounds; not liking when babies cry, dogs bark, or sirens; slow auditory processing

Visual- poor depth perception making stairs an uneven surfaces challenging

Oral- picky eater; grind teeth; chew on non-edibles

Proprioception- stuff food in mouth; difficulty regulating force

Interoception- difficulty feeling thirst or satiation; difficulty with toilet training; high pain tolerance

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Who can help?

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What is Occupational therapy?

- Health profession concerned with how people function in their respective roles and how they perform meaningful activities.
- "Occupation" is any activity in which one engages throughout the day.

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Role of OT in sensory processing

- An OT will assess what is interfering with a person's ability to engage in activities and often it can be an impaired sensory system.
- Often direct therapy in an outpatient setting.
- Sensory diet is provided.
- Often it is trial and error to determine the "best" sensory activities for each person.
- Modifications can be made in a classroom/work/day program setting as well.

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Sensory Diet

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What is a sensory diet?

- Designed to provide the right combination of sensory input to keep an optimal level of arousal or performance.
- Should be more like choosing from a menu rather than following a recipe.
- Needs to be individualized and may not necessarily be convenient.
- Sensory input should NEVER be given as a reward or removed as a punishment.

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Activities in a sensory diet

- Alerting
 - Benefits the under-responsive person; someone who need a boost.
- Organizing
 - Activities that help regulate the person's responses so they can be more attentive.
- Calming
 - Activities that help decrease the sensory over-responsiveness.

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Sensory diet

- Sensory accommodations
 - Used to address difficulties with sensations involving sight, sound, touch, taste, and smell
- Sensory activities
 - Used to address input to the muscles and joints

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Sensory accommodation examples

- Sunglasses, dim lighting, study corral
- Headphones
- Gloves, clothing without labels, fidget
- Bland foods for flavor vs spicy foods or soft/pureed foods vs crunchy foods
- Air purifiers, limiting perfume/lotion scents and air fresheners or aromatherapy

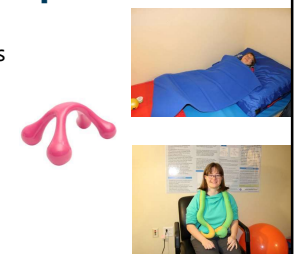
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Sensory activity examples

Proprioceptive input

- Everyday activities like chores
- Joint compression
- Physical activity
- Vibration
- Weighted objects



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Proprioceptive Input

Many individuals with Down syndrome experience difficulty with their proprioceptive senses in our body are responsible for providing feedback to the brain. When these senses aren't working like they should, it can be difficult to coordinate, meaning they appear clumsy. This is why many individuals with Down syndrome have difficulty grasping things like a pencil or a spoon. These activities may vary but they often appear stumped over or off-balance.

Affordable Sensory Equipment Recommendations

Weighted products:
Key points to remember: Please consult with an Occupational Therapist to help you determine the best size and weight. It is typically recommended to have a blanket be 7-10% of a person's body weight.

Weighted blankets and lap pads:
Custom weighted blankets and lap pads:
<http://www.sensoryblends.com/weighted-blankets/>
Amazon and they even carry weighted products.

Weighted socks:
Amazon has a few vendors (be careful though because there are many fakes).

Alternative ideas to expensive weighted objects:
Down stoppers and neck wraps and warmers
Available at drug stores and websites like Amazon, Bed Bath and Beyond carries a brand called Bed Buddies.
Talk with your dentist as you may be able to get an old lead unit used for a x-ray.

Vibration:
Massage
Hand held massager: Amazon carries a brand by Dr. Schulz's
Vibrating cushion: Amazon carries a brand by Dr. Schulz's

Upper body
Weighted blankets provide joint compression, push, or weight to strengthen body awareness and track in space, as well as for joint stabilization and can be used during, morning, and evening to help calm the body. Therefore, complete the back in bed and head on with Down syndrome. It should only be a few weeks. (DHS) at 847-316-2001 or
to use the form. If they want to be used to obtain joint compression can

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Down Syndrome Sleep Tight Weighted Blankets provide joint compression, push, or weight to strengthen body awareness and track in space, as well as for joint stabilization and can be used during, morning, and evening to help calm the body. Therefore, complete the back in bed and head on with Down syndrome. It should only be a few weeks. (DHS) at 847-316-2001 or to use the form. If they want to be used to obtain joint compression can

- Cotton weighted blanket - joint compression is swaddling
- 100% polyester weighted blanket - joint compression is swaddling
- Polyester weighted blanket - joint compression is swaddling
- Suitable for all ages
- 5 lb. blanket fits users 25" x 36"
- 8 lb. blanket fits users 36" x 42"
- 12 lb. blanket fits users 42" x 54"
- 16 lb. blanket fits users 48" x 72"
- 25 lb. blanket fits users 54" x 72"
- Machine washable
- Made in the USA and imported materials
- Sleep Tight Weighted Blankets

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Behavioral strategies

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Strategies for Increasing Behavioral Success

- Seek to understand the function of the behavior and determine ways to meet the need.
- Increase predictability.
- Set guidelines early on.
- Use of visual supports gives individual some control.
- Ensure needs are being met-- sleep, food, social engagement, physical activity, etc.

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Strategies for Increasing Behavioral Success

- Tell the person what to do instead of what not to do.
- Show the person by modeling or using a picture of the action.
- Clearly and simply state what you expect the person to do.
- Manage your own reaction to the behavior.

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Strategies for Increasing Behavioral Success

- Remember individuals with DS use inappropriate behavior because they may not understand the social rules yet.
- Talk to individuals with DS using language they understand.
 - They may not understand words like "don't" because it is a short word for "do not" and he/she may not know what the "negation" of a word means.

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Strategies for Increasing Behavioral Success

- Encourage the person in a way that lets him/her know that he/she is exhibiting the desired behavior
 - Use specific language rather than "good job"
- Be enthusiastic and generous with encouragement and praise.
- Be strategic and cautious with consequences and/or punishment.
- Stick with it. Be consistent.

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Strategies for Increasing Behavioral Success

Function	Strategies
Attention	Seeking: check-ins, special jobs, dedicated time to share interests, opportunities for more interaction during the day, regular praise Avoiding: breaks, teach social skills for declining attention
Access (items/activities/locations)	Reward systems, giving choices, plan/schedule time for access, visual timers
Escape/avoidance	Allow breaks, teach coping strategies, arrange the environment, prep for transitions
Sensory	Movement breaks, sound cancelling headphones, adjust lighting, quiet spaces, sensory tools

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Visual supports

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What are visual supports?

Pictures, words or other images that are used to...

- Help communicate
- Share or manage expectations
- Provide reminders/offer choices
- Teach new information/Maintain skills & independence
- Facilitate understanding of challenging situations

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Using visual supports to promote positive behavior

- Visual supports help to provide/establish structure and routine.
- Allow for greater independence by providing memory and comprehension strategies.
- Lessen the battle between parent/caregiver and person with DS.
- Help teach what to do.
- Can provide motivation.
- Provides opportunity to offer choices.
- Eliminates need to process instructions auditorily.

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How can visual supports be implemented?

Help communicate

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How can visual supports be implemented?

Share or manage expectations

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How can visual supports be implemented?

Provide reminders

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How can visual supports be implemented?

Teach new information

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How can visual supports be implemented?

Facilitate understanding

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Tricks to help Behavior

- Clearly defined rules and expectations.
- Consistent rewards and reasonable consequences.
- CONSISTENCY.
- Set boundaries.
- Offer choices.
- Use visual supports.
- Address the function

Sensory

- Provide sensory input at regular intervals. About once every 2 hours or so.
- Positive time out in a calm space.
- Determine sensory triggers and find ways to avoid/modify/adapt to them.

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Things to remember

- Behaviors happen. The question to ask yourself is whether the behavior *needs* to change.
- Rule out medical causes for behaviors.
- Consider sensory approaches even if you determine it is truly a problematic behavior.
- Be firm and set guidelines.
- Make sure the intervention matches the function.
- Manage expectations by telling the person with DS what you want them to do.
- Use visual supports to support positive behaviors.

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Resource Library

All resources: <https://adsresources.advocatehealth.com>

Sensory resources: <https://adsresources.advocatehealth.com/resources/?category=Sensory>

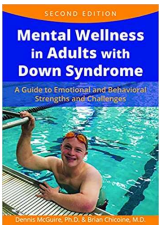
Behavior resources: <https://adsresources.advocatehealth.com/search/?keyword=behavior>



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Free copy of the Mental Wellness book



<https://adsresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/>

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Facebook

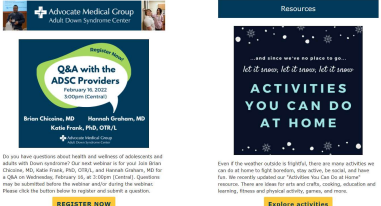


<https://www.facebook.com/adultdownsyndromecenter>

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Email list




<http://eepurl.com/c7uV1v>

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Additional Resources



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Books

- Kranowitz, C.S. (2005). *The Out-of-Sync Child*. New York, NY: Penguin Group.
- Kranowitz, C.S. (2016). *The Out-of-Sync Child Grows Up*. New York, NY: Penguin Group.
- Miller, L.J. (2006). *Sensational Kids: Hope and Help for Children with Sensory Processing Disorder*. New York, NY: Penguin Group.
- Slutsky, C.M. & Paris, B. (2004). *Is it Sensory or is It Behavior?* New York, NY: PsychCorp.
- Stein, D. (2016). *Supporting Positive Behavior in Children and Teens with Down Syndrome: The Respond but Don't React Method*. Bethesda, MD: Woodbine House.
- Voss, A. (2015). *Understanding Your Child's Sensory Signals, 3rd ed.* San Bernardino, CA: CreateSpace Independent Publishing Platform.
- Yack, E., Aquilla, P., & Sutton, S. (2002). *Building Bridges through Sensory Integration, 2nd ed.* Arlington, TX: Future Horizons.

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Websites-General

- <https://www.spdstar.org/>
- <http://sensoryfun.com/home>
- <http://www.asensorylife.com>
- <https://sensationalbrain.com/>
- <https://www.amctheatres.com/programs/sensory-friendly-films>

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Websites-Sensory diet

- http://sensorysmarts.com/sensory_diet_activities.html
- http://www.superduperinc.com/handouts/pdf/132_sensory_diet_090212.pdf
- <http://www.developmental-delay.com/page.cfm/286>
- <http://sensorysmarts.com/sensory-diet.pdf>
- <http://www.alertprogram.com/index.php>

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Websites-Equipment

- <http://www.specialneedstoys.com/>
- <http://www.southpawenterprises.com/>
- <http://www.therapro.com/>
- <http://www.flaghouse.com/>
- <http://www.therapyshoppe.com/>
- <http://store.schoolspecialty.com>

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Contact information

Katie Frank, PhD, OTR/L
Katherine.frank@aah.org

Abby Rowley, LCSW
abigail.rowley@aah.org

Adult Down Syndrome Center,
 1610 Luther Lane, Park Ridge, IL 60068
 P:847-318-2303

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