

Is it Sensory or is it Behavior?

Strategies to Support Individuals with Down Syndrome

April 27, 2024

Katie Frank, PhD, OTR/L | Occupational Therapist



Behavior

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.

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

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 without permission
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

Common characteristics that may impact behavior in DS

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

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

What can cause problematic behavior?

Mental health causes

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

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

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.**

Social causes

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

How do we address problematic behavior?

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

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.

Strategies

Health

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

Non-medicinal / non-health

- Sensory
- Structure / routine
- Social supports

Is it sensory or is it behavior?

Sensory or behavior?

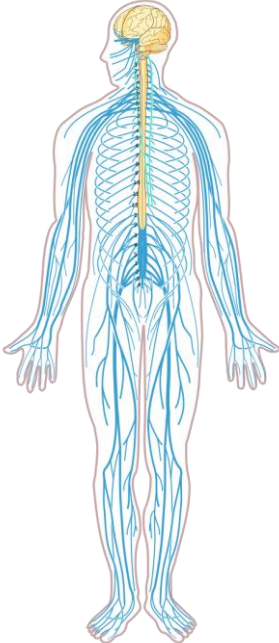
- It can be both.
- Sometimes the only way to tell depends on which interventions are working...either sensory or behavior management.
- Sensory input should NEVER be removed as part of a behavior plan. Input is not a reward either.
- An approach that utilizes both sensory input and behavior management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

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?

Our Sensory System

Our sensory system



Our sensory system



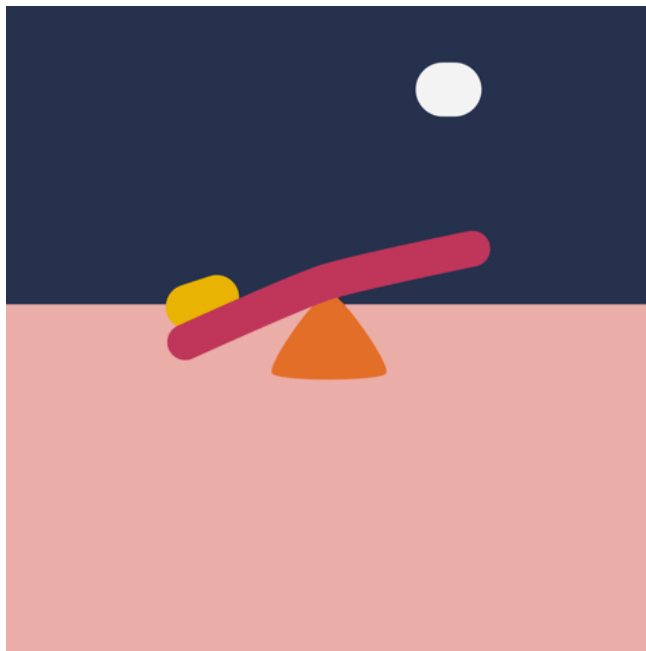
Sensory and behavior



The kink can impact behavior.

We may see...

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



There are 8 senses!

Far Sensory Systems

Touch
Sight
Smell
Sound
Taste

Near Sensory Systems

Vestibular
Proprioception
Interoception

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 and 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

Who can help?

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.

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.

Sensory Diet

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.

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.

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

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

Sensory activity examples

Proprioceptive input

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



Proprioceptive Input

Many individuals with Down syndrome experience difficulty with their proprioceptive sensors in our body are responsible for providing feedback that the body is in space. When these sensors aren't working like they should, it can lead to difficulty with motor coordination, meaning they appear clumsy. This is because they are unable to actually carry out a movement even though they know how to plan it. They may carry out activities and have difficulty grading the things too hard or too soft. Another feature is the person may have difficulty sitting upright; they often appear slumped over or lethargic.

In order to activate these receptors and improve a person's proprioceptive activities can be encouraged throughout the day to get natural input. These activities can be done in preparation for a transition or when you start working up. For instance, they need to complete a series of self-care tasks that require verbal prompts to initiate the activity. Provide proprioceptive input to the body and prepare to complete the required task. This also goes for transitions, like leaving the house and your loved one with DS doesn't want to go? Try to help them transition. These activities may not be effective once they experience a melt-down.

- Animal walking (like bear or crab, even crawling like a cat or dog, or hopping like a bunny)
- Jumping up and down, maybe even on a trampoline
- Dancing
- Jumping Jacks
- Push-ups on the floor or against the wall
- Bouncing on a therapy ball
- Sitting on a sit-disc
- Riding a bike/scooter
- Sports like swimming, yoga, Pilates and martial arts
- Completing an obstacle course
- Carrying a heavy backpack
- Moving furniture
- Pushing a cart/stroller/wagon
- Rolling up in a blanket like a burrito
- Bear hugs or being squeezed between pillows or cushions
- Using play dough
- Log rolling
- Vibration
- Weighted blankets
- Sitting in a rocking chair
- Strength training or light weights
- Throwing and catching objects
- Joint compression
- Massage
- Yard work
- Housework like mopping, vacuuming, or sweeping
- Eating chewy foods
- Sucking through a straw

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

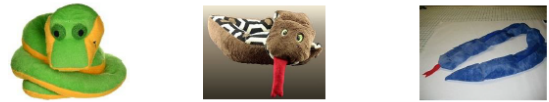
Custom weighted blankets and lap pads:

- <http://www.sensacalm.com/weighted-blankets/>
- <http://www.mosaicweightedblankets.com/> (they even offer DIY kits)

Amazon and Etsy even carry weighted products

Weighted snake

Amazon has a few versions (be careful though because their prices fluctuate).



Alternative ideas to expensive weighted objects



Door stoppers and neck wraps and warmers. Available at drug stores and websites like Amazon. Bed Bath and Beyond carries a brand called Bed Buddy.

Talk with your dentist as you may be able to get an old lead vest used for x-rays.

Vibration:

Hand held massager: Amazon as well as drug stores, Target, WalMart etc.

Vibrating cushion: Amazon carries a brand by Dr.Scholl's

Upper body

ive input. It occurs when there is compression, push, or weight r developing body awareness and body in space, as well as for joint i-regulation and can be very calming, regulating, and organizing for chnique that seems to be effective for individuals with Down

rell as to help calm the body. Therefore, complete this quick activity your loved one with Down syndrome. It should only take a few

ank, PhD, OTR/L at 847-318-2331 or

or on the floor. If they want or need to stand, joint compression can



u touch him/her. Once joint compression becomes part of the s time for joint compression.

side and you will plan on doing joint compression to both sides.

her shoulder and your other hand on his/her upper arm. Gently ther to provide compression at the shoulder joint. Do this 10 times.





Details

Our Sleep Tight Weighted Blankets provide gentle pressure which encourages a restful night sleep.

- Gentle pressure of weighted blanket replicates the experience as swaddling
- 100% Cotton
- Polyester inner core filled with glass pellets
- Suitable for all ages
- 5 lb. blanket fits users 28" x 36"
- 8 lb. blanket fits users 30" x 36" x 42"
- 12 lb. blanket fits users 32" x 42" x 54"
- 16 lb. blanket fits users 34" x 48" x 72"
- 25 lb. blanket fits users 36" x 54" x 72"
- Machine Washable
- Made from natural and imported materials
- Available in Sleep Tight Weighted Blanket

Behavioral strategies

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.

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.

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.

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.

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

Visual supports

Using visual supports to promote positive behavior

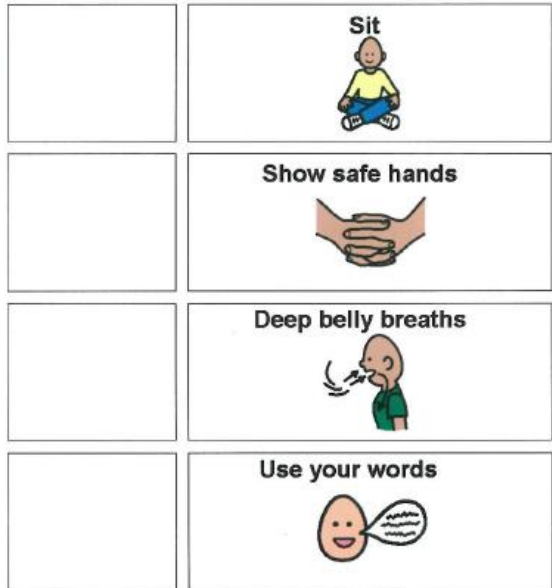
- Visual supports help to provide/establish structure and routine.
- Allow for greater independence by providing memory and comprehension strategies.
- Lessen the battle between parent/caregiver and person with DS.
- Help teach what to do.
- Can provide motivation.
- Provides opportunity to offer choices.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

How can visual supports be implemented?

Help communicate



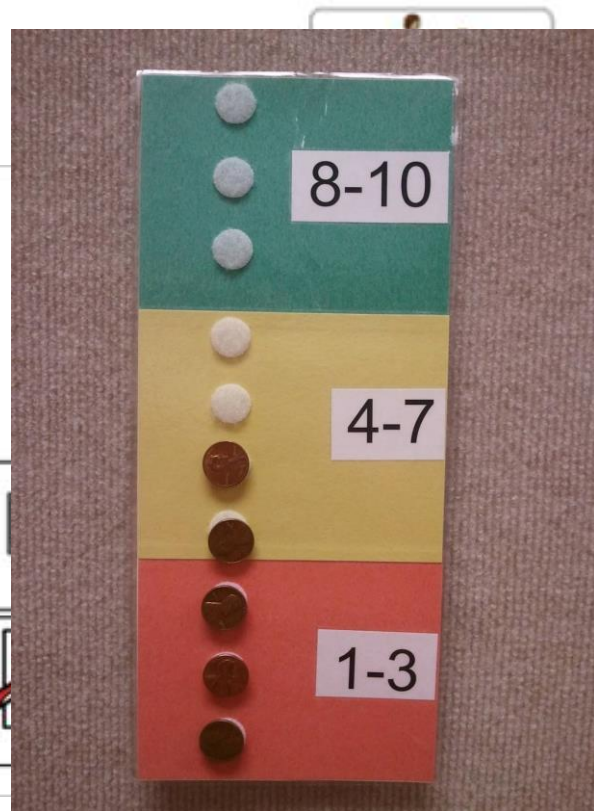
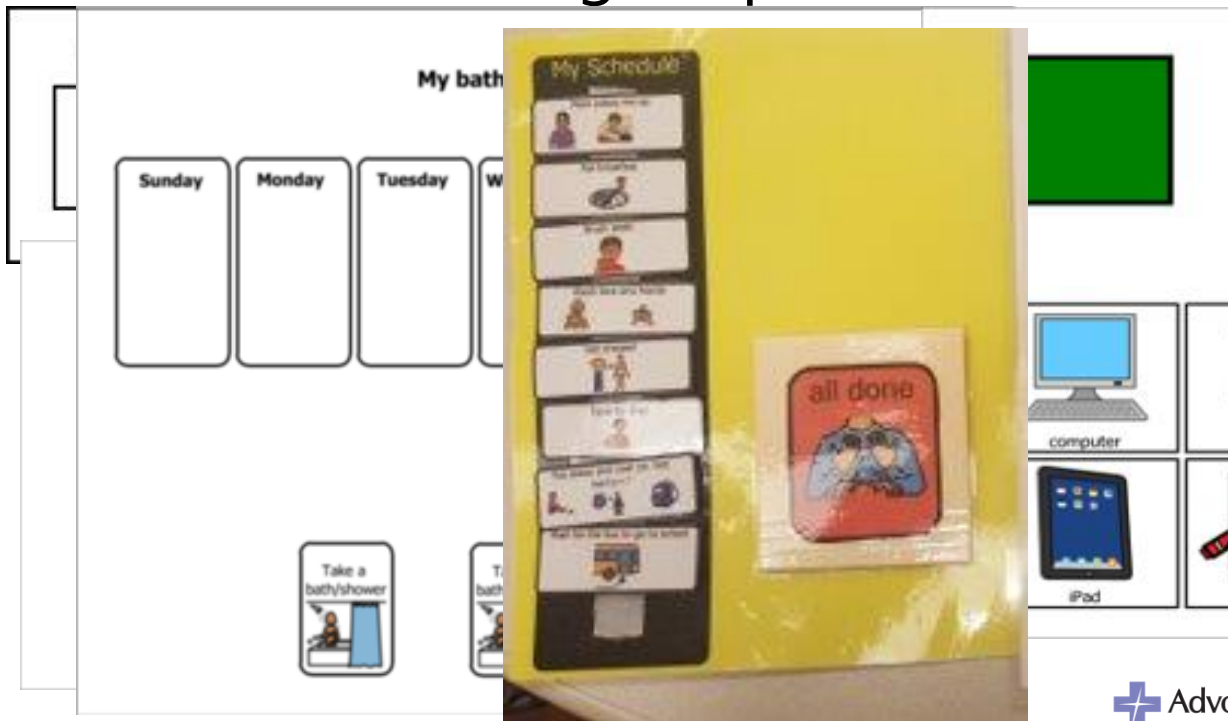
How to Show I'm Calm



Advocate Medical Group
Adult Down Syndrome Center

How can visual supports be implemented?

Share or manage expectations



How can visual supports be implemented?

Provide reminders



How can visual supports be implemented?



Teach new information

's Shower Routine



 <p>Get wet</p>	 <p>Wash face and head</p>	 <p>Rinse</p>	 <p>Wash back, chest, arms</p>	 <p>Rinse</p>
 <p>Wash privates</p>	 <p>Rinse</p>	 <p>Wash legs and feet</p>	 <p>Turn water off</p>	 <p>Dry off</p>

Strategies To Help Me Calm Down



CALM BREATHING

 <p>pretend to smell a flower to inhale</p>	 <p>pretend to blow out a candle to exhale</p>
--	---

CALM THOUGHTS

 <p>squeeze hands</p>	 <p>count to ten</p>
--	---

CALM MUSCLES

 <p>be loose like a statue</p>	 <p>be loose like an inflatable man</p>
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Page 1 of 1
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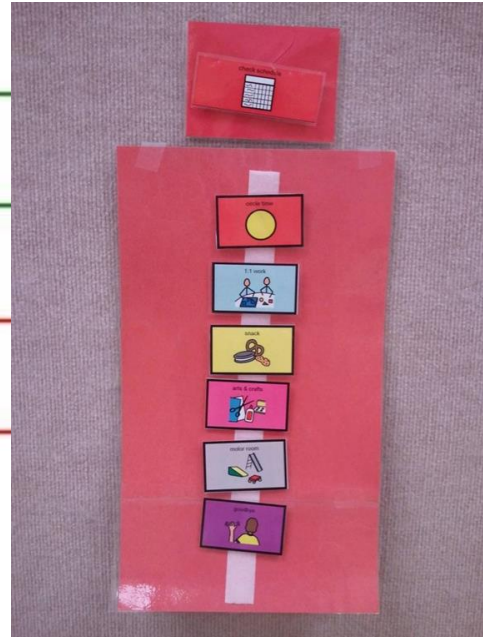
How can visual supports be implemented?

Facilitate understanding

Going for a sleep study



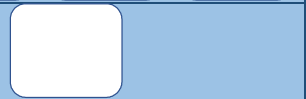
maxiSHARE



Princesses use
Kind words
Safe Hands



Waiting for...



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.

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.

Resource Library

All resources:

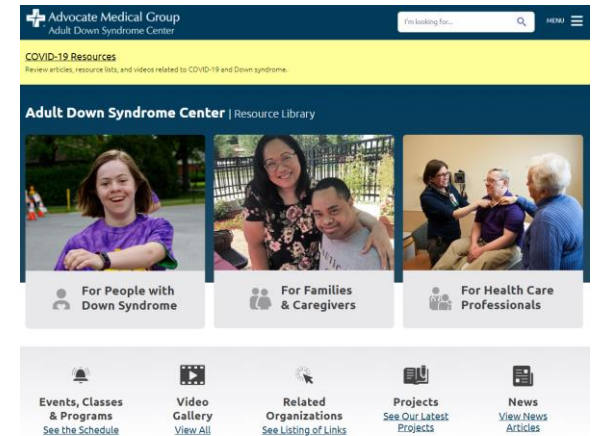
<https://adsresources.advocatehealth.com>

Sensory resources:

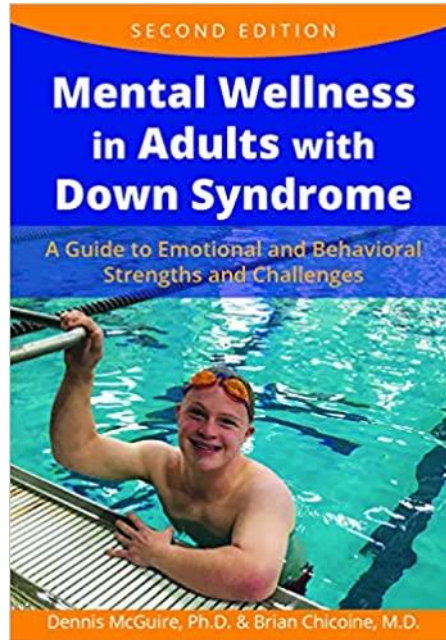
<https://adsresources.advocatehealth.com/resources/?category=Sensory>

Behavior resources:

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



Free copy of the Mental Wellness book

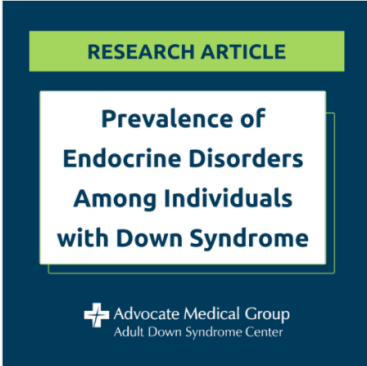


<https://adsresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/>

Facebook

Adult Down Syndrome Center
January 31 at 7:00 AM · 🌐

We are excited to share the recent publication of our study on the prevalence of endocrine disorders in individuals with Down syndrome. The Adult Down Syndrome Center collaborated with the Advocate Aurora Research Institute and University of Chicago. Individuals with Down syndrome were more likely to have thyroid disorders, type 1 diabetes, and gout and less likely to have type 2 diabetes than their age- and sex-matched counterparts. The findings highlight the need for health... See more



RESEARCH ARTICLE

Prevalence of Endocrine Disorders Among Individuals with Down Syndrome

Advocate Medical Group
Adult Down Syndrome Center


👍 60 45 Shares

👍 Like 💬 Comment ➦ Share

Adult Down Syndrome Center
January 25 at 7:00 AM · 🌐

Fear of heights is a common fear identified by individuals with Down syndrome and their families who come to our clinic. The providers at the Adult Down Syndrome Center have observed that many people with Down syndrome seem to have a difference in depth perception which may contribute to this fear. In the article linked below, Dr. Brian Chicoine shares more on this topic, including ways to support a person with Down syndrome who may have a fear of heights.

<https://adsresou...> See more



Fear of heights in people with Down syndrome


Advocate Medical Group
Adult Down Syndrome Center

👍 95 27 Comments 46 Shares

👍 Like 💬 Comment ➦ Share

Adult Down Syndrome Center
January 20 at 7:00 AM · 🌐

Visuals can assist people with and without Down syndrome in many ways. We do not think that they are something that we "outgrow." In fact, many of us use visual supports (such as apps on our phones, to-do lists, calendars, etc.) on a daily basis! They can be used to set and manage expectations, establish routines, communicate, learn new skills, and more. Our occupational therapist Dr. Katie Frank shares information about the use of visual supports in the article from our Reso... See more



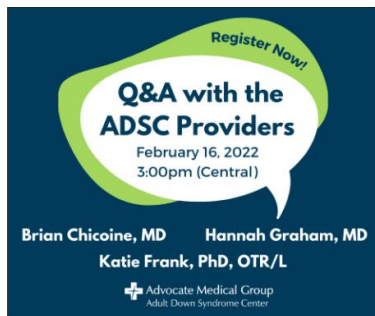
Visual Supports for Adolescents & Adults with Down Syndrome

Katie Frank, PhD, OTR/L

👍 98 9 Comments 52 Shares

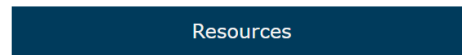
<https://www.facebook.com/adultdownsyntaxromecenter>

Email list



Do you have questions about health and wellness of adolescents and adults with Down syndrome? Our next webinar is for you! Join Brian Chicoine, MD, Katie Frank, PhD, OTR/L, and Hannah Graham, MD for a Q&A on Wednesday, February 16, at 3:00pm (Central). Questions may be submitted before the webinar and/or during the webinar. Please click the button below to register and submit a question.

[REGISTER NOW](#)

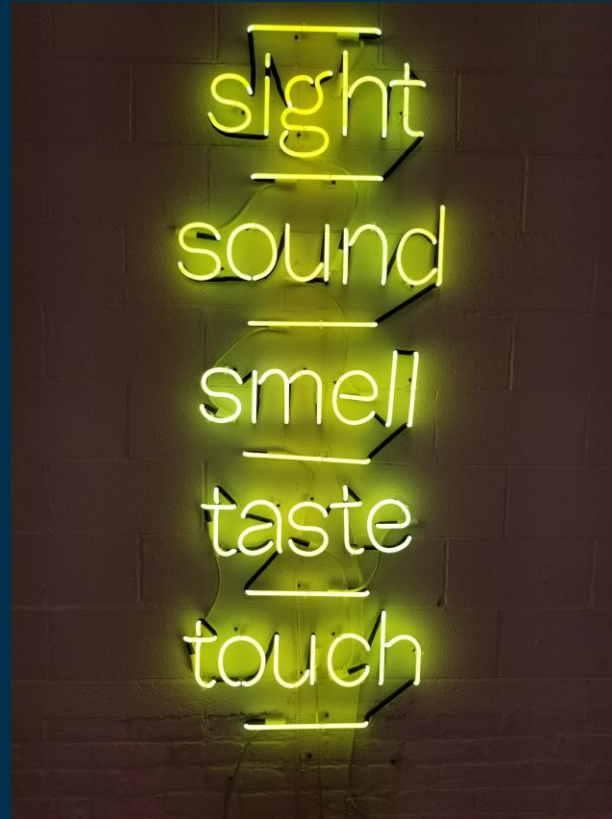


Even if the weather outside is frightful, there are many activities we can do at home to fight boredom, stay active, be social, and have fun. We recently updated our "Activities You Can Do at Home" resource. There are ideas for arts and crafts, cooking, education and learning, fitness and physical activity, games, and more.

[Explore activities](#)

<http://eepurl.com/c7uV1v>

Additional Resources



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.

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>

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>

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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