# **Is it Sensory or is it Behavior?**

**Strategies to Support Individuals with Down Syndrome** 

April 22, 2023

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#### **Adult Down Syndrome Center**





Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.

#### Disclaimer

This information 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.

### Today's agenda

- Determine how to access whether it is a sensory need or a behavioral issue.
- Understand sensory processing and how it impacts individuals with Down syndrome.
- Share practical sensory activities and suggestions for affordable equipment.
- Share behavioral strategies.

## **Behavior and Behavior Change**



#### 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

#### **Behavior change**

- A new action or pattern of actions that are atypical for an individual.
- Is the change in behavior interfering with the individual's ability to function effectively?
- How does the change in behavior impact the family?
- What is the individual trying to communicate?
  - Needs, desires, challenges

# **Examples of behavior challenges in DS**

- Increase in self-talk
- Exhibiting new obsessivecompulsive 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

# Common characteristics that may impact behavior in DS

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

#### What can cause a behavior change?

## Causes of behavior changes

- Health
  - Mental
  - Physical
- Sensory
- Social

#### 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.

#### How do we address behavior change?

## **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?

## 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?



- 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 yourself...

- 1. Does the person's action disrupt your life? For example, do you avoid certain places because of noises, crowds or smells etc.?
  - If yes, then sensory
- 2. Does the action occur with *everyone*?
  - If yes, then sensory
- 3. Does the person stop the action when given a reward?
  - If yes, then behavior

#### **Common reactions**

#### **Behavior**

- Person can turn reaction on and off like a switch.
- Cry or tantrum, but usually without tears.
- Responds well to structure and boundaries.

- Unable to calm self down immediately, even after they get what they want.
- Response is the same with everyone.

"He has a meltdown every night during his bedtime routine."

"He is more compliant with toothbrushing for dad than for mom."

1

Sensory

2

## Behavior

"She bites her brother when he takes her toy." when she is frustrated."

"She bites her wrist

## Behavior

"He acts out when mom is taking care of his baby sister."

"He acts out during transitions."

1

Behavior

2

## **Tricks to help**

#### **Behavior**

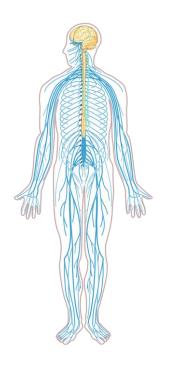
- Clearly defined rules and expectations.
- Consistent rewards and reasonable consequences.
- CONSISTENCY.
- Set boundaries.
- Offer choices.
- Use visual supports.

- 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.

## **Our Sensory System**



### Our sensory system





### Our sensory system





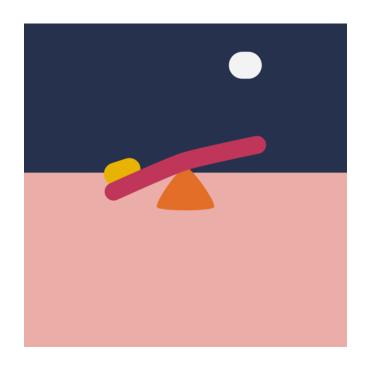
### **Sensory and behavior**



The kink can impact behavior.

We may see...

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



#### What is Sensory Processing Disorder?

# Sensory processing disorder (SPD)

- Umbrella term to cover a variety of neurological disabilities
- Problems with the ability to process information received through the senses which impact the ability for a person to function in their daily life.
- SPD happens in the Central Nervous System which starts with the brain. When processing is disorderly, the brain cannot do its most important job of organizing sensory messages.

#### 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 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

### 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 times it can be an impaired sensory system.
- Not all OTs are as comfortable working with individuals who have sensory dysfunction.
- While there are formal assessments to "diagnose" Sensory Processing deficits, individuals with DS may not tolerate them.

## Testing for sensory processing differences

- Sensory Processing Measure 2
- Sensory Profile 2 and Adolescent/Adult Sensory Profile
- SIPT and Sensory Processing Three Dimension Scale
- The Sensory Symptoms Checklist

https://sensationalbrain.com/pdf/SB-sensory-checklist.pdf



#### Sensory Symptoms Checklist

The following checklist is not a diagnostic tool; rather, it is an indicator of sensory over- or under-responsiveness. The purpose of this tool is to assist in developing an appropriate treatment plan and/or sensory diet for an individual with sensory modulation difficulties.

Remember: It is normal for all people to be sensitive to certain sensations. Sensory modulation becomes a disorder only when it negatively impacts a person's life (i.e., ability to pay attention, learn, socialize, relax).

The asterisk (\*) indicates sensory-seeking behavior. Sensory Seeking is a form of underresponsiveness, but these individuals seek intense sensation to compensate for the underresponsiveness of their nervous systems.

#### TACTILE (TOUCH)

Symptoms of Over-Responsiveness	Symptoms of Under-Responsiveness
avoids affectionate touch	always touching others*
bothered by seams in clothing, tags,	as a young child, may prefer to be
waistbands, etc.	without clothes and barefoot
avoids messy play including finger-	doesn't seem to notice messy hands or
painting and Play-Doh	face
dislikes nail-trimming/hair-cutting hair-	touches everything, brings objects and
brushing/tooth-brushing	toys to mouth frequently*
limited food preferences, sensitive to	may stuff too much food in mouth
food textures	seems unaware of light touch
excessively ticklish	doesn't seem to notice cuts and
avoids standing close to others	scrapes, doesn't mind shots
startles easily when touched	drools, doesn't wipe runny nose
unexpectedly	unintentionally rough on pets or other
overreacts to minor injuries or	kids
mosquito bites	craves intense flavors-salty, sweet,
	sour, spicy, etc.*
*Indicates concern cooking behavior	difficulty with fine motor tasks

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#### PROPRIOCEPTIVE (PRESSURE ON MUSCLES AND JOINTS)

Since proprioceptive input is always helpful to the nervous system, we do not see *over-responsivity* in this category.

	Symptoms of Under-Responsiveness
	loves jumping, climbing, wrestling, and crashing activities* walks on toes or walks heavily* difficulty with fine motor tasks prefers crunchy and chewy foods* sucks thumb or fingers, chews on clothes and toys
	grinds teeth, cracks knuckles* loves tight hugs and "squishing" activities or positions* chooses thick or heavy blankets
	self-abusive behaviors—pinching, biting, head-banging* prefers tight-fitting clothes or may wear a snug jacket constantly* uses too much or too little force on objects (e.g., juice boxes, crayons)
ESTIBULAR (MOVEMENT)	Symptoms of Under-Responsiveness
as a baby, dislikes being held away from adult's body or tossed in air, may be "clingy"	as a baby, needs to be rocked a lot, is happiest in stroller, swing, bouncer* dislikes sedentary tasks*
avoids swings, slides, anything that requires feet to be off the ground	is in constant motion, loves spinning, swinging, being upside down*
fearful of escalators, elevators, and all heights gets motion sick easily	may have low muscle tone (muscles and joints seem too soft and floppy) "W" sitting on floor, slumps, leans in
dislikes leaning back for hair- washing or floating on back in pool	chair loves spinning, loves amusement park rides, is a "thrill-seeker"*
ndicates sensory-seeking behavior.	rocks self or moves head back and forth

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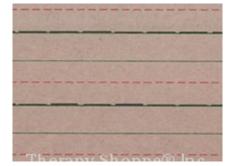
# Role of OT in sensory processing

- Often direct therapy in an outpatient setting.
- Sensory diet is provided.
  - Can include a combination of alerting, calming, and organizing activities.
- 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.

# **Examples of classroom** modifications



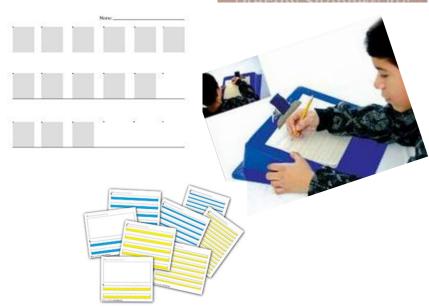
# **Examples of classroom** modifications











### **Other Classroom Considerations**

- Endurance
  - Positioning techniques
- Hearing
  - Placement in classroom
  - Visual supports
- Vision
  - Placement in classroom
  - Altered materials
- Attention
  - Placement in classroom
  - Frequent breaks/alternating work and play tasks
  - Use of a visual schedule
  - Sensory seating

## **Sensory Diet**

### What is a sensory diet?

- Designed to provide the right combination of sensory input to keep an optimal level or 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.

# Types of 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 overresponsiveness.

### **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 feed body is in space. When these sensors aren't working like they should difficulty with motor coordination, meaning they appear clumsy. This ability to actually carry out a movement even though they know how t planning. They may carry out activities and have difficulty grading the things too hard or too soft. Another feature is the person may have di they often appear slumped over or lethargic.

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

#### 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.

Affordable Sensory Equipment Recommendations

#### 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).





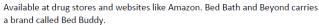


#### Alternative ideas to expensive weighted objects



Door stoppers

and neck wraps and warmers



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

#### Vibration:

Using play

Log rollina

Vibration

Weighted

Sitting in a

Rocking in

Strength tr

or light we

Throwing a

Joint comp

complete j

Yard work

House wor

mopping, \

down the c

Eating che

Sucking th

Massage



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



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



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

rank, 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.







#### De S

p Tight Weighted Blankets provide ressure which couraging a restful night sleep

- Gel weighted blanket g erience as swaddling.
- 100%
- Polyester in dispellets
- Suitable for all
- 5 lb. blanket fits us
   2" x 36"
- 8 lb. blanket fits users
   8 s 36" x 42".
- 12 lb. blanket fits 2" x 54"
- 16 lb. blanket "x 72"
- 25 lb. blap (os. +,
- Machi
- M<sub>2</sub> and imported mater.
- Sleep Tight Weighted Blank

## Sensory input and behavior

- Difficulties with processing sensory input can impact our behavior.
- Incorporating sensory strategies throughout the day can make transitions easier.
- Sensory input can help decrease anxiety.
- Regular intervals of sensory input can help prevent emotional outbursts.
- Sensory input can be used as a recovery strategy if an emotional outburst is unpreventable.

## **Behavioral strategies**



## Strategies for Increasing Behavioral Success

- Increase predictability.
- Set guidelines early on.
- When in doubt incorporate music.
- Use of visual supports gives individual some control.
- 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.

## Strategies for Increasing Behavioral Success (cont.)

- 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.
- Encourage the person in a way that lets him/her know that he/she is exhibiting the desired behavior
- Be enthusiastic and generous with encouragement and praise.

## Visual supports

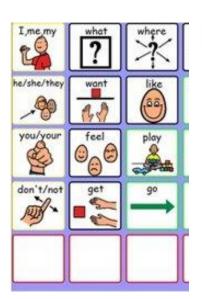
# What are visual supports?

- 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

## Why are visual supports important in supporting positive behavior?

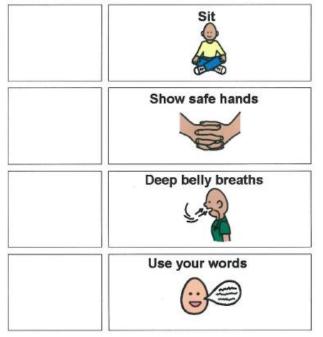
- Visual supports help to provide/establish structure and routine.
- Allow for greater independence by providing memory and comprehension strategies.
- Lessen the battle between parent/caregiver and person with DS.
- Help teach what to do.
- Can provide motivation.
- Provides opportunity to offer choices.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

Help communicate



How to Show I'm Calm

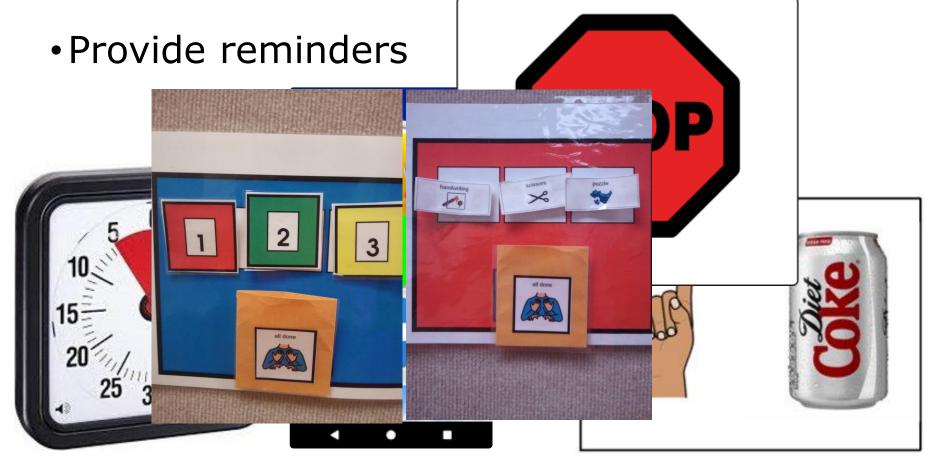






Share or manage expectations





Teach new information



#### Strategies To Help Me Calm Down

#### CALM BREATHING





#### **CALM THOUGHTS**



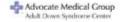


#### CALM MUSCLES

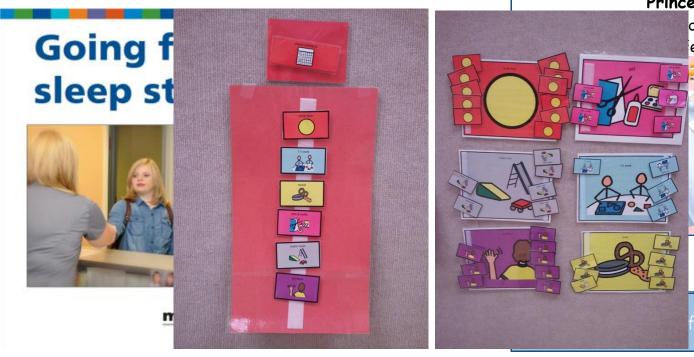


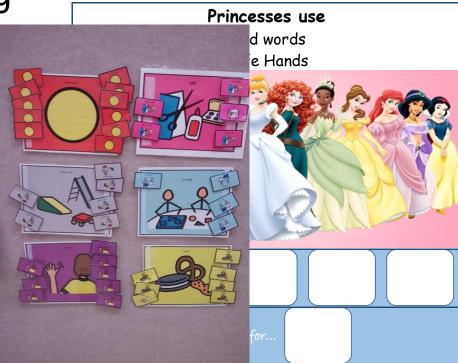


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Facilitate understanding





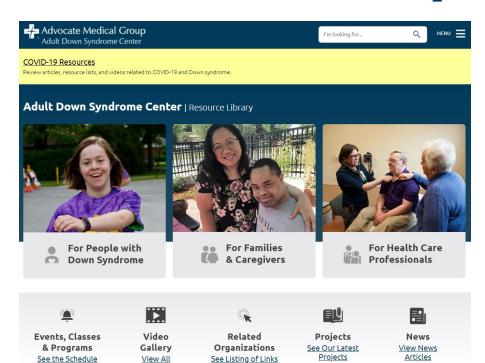
## Visual supports and behavior

- Improve quality of life.
  - Promoting independence
  - Facilitating communication
  - Teaching new skills
- Help avoid emotional outbursts.
  - Establishing routine/structure
  - Managing expectations
  - Offer choices
- Facilitate understanding of challenging situations.

### 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.
- Manage expectations by telling the person with DS what you want them to do.
- Use visual supports to support positive behaviors.

### **Resource Library**

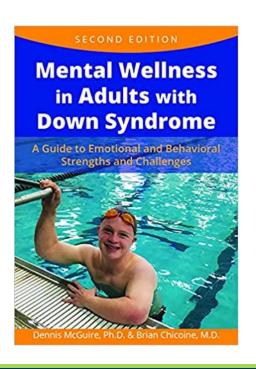


https://adscresources. advocatehealth.com

All Resources

**Sensory Resources** 

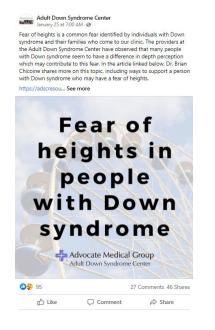
### Free Copy of the Mental Wellness book



https://adscresources. advocatehealth.com/ mental-wellness-inadults-with-downsyndrome-2ndedition/

#### Facebook







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



https://www.facebook.com/adultdownsyndromecenter

### **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, Php, 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, MY: 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, 3<sup>rd</sup> ed. San Bernardino, CA: CreateSpace Independent Publishing Platform.
- Yack, E., Aquilla, P., & Sutton, S. (2002). Building Bridges through Sensory Integration, 2<sup>nd</sup> 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/sen sory-friendly-films

### **Websites-Sensory diet**

- http://sensorysmarts.com/sensory diet activ ities.html
- http://www.superduperinc.com/handouts/pdf /132 sensory diet 090212.pdf
- http://www.developmentaldelay.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

### Personal contact information

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