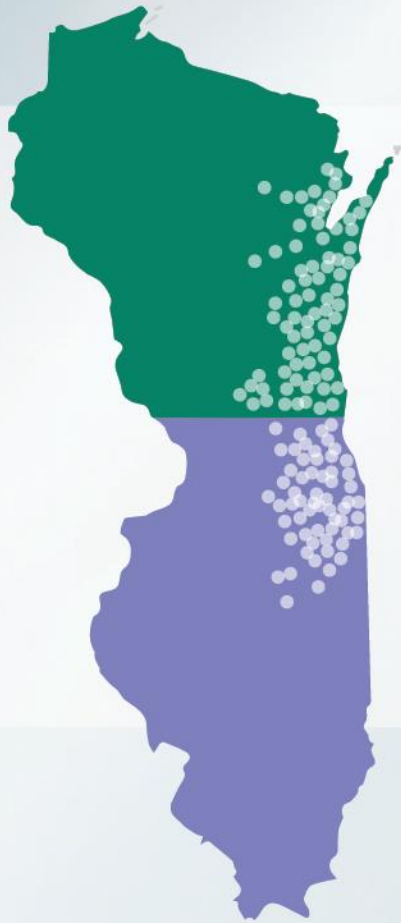




Behavior Changes in Adolescents and Adults with Down Syndrome

Adult Down Syndrome Center

April 28, 2020 | Brian Chicoine, MD & Katie Frank, PhD, OTR/L

Resource Library Link and Q&A

Link

Behavior Changes in Adolescents & Adults with Down Syndrome

Support **ADSC Resource Library**

adscresources.advocatehealth.com

Q&A

 Skype Q&A

Your name (optional)

Type your question here

ask

ask anonymously

top

all

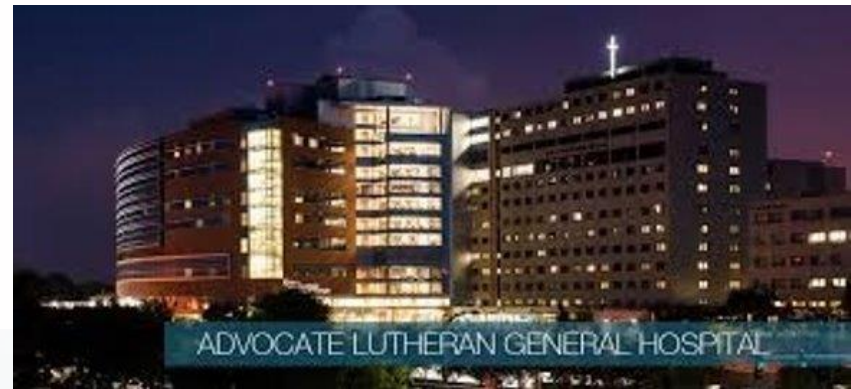
my questions

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.

Adult Down Syndrome Center

Park Ridge, IL





Brian Chicoine, MD



Katie Frank, PhD, OTR/L

Objectives

- Define behavior change
- Identify reasons for behavior changes
- Discuss strategies and solutions to address behavior changes

What is a behavior change?

Definition of behavior change

- A new action or pattern of actions that are atypical for an individual

Behavior changes – things to note

- 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 changes

- Appearing depressed, anxious, or stressed
- Exhibiting new obsessive compulsive behaviors
- Becoming agitated or aggressive
- Regressing
- Throwing tantrums or having meltdowns
- Being non-compliant

What can cause a behavior change?

Causes of behavior changes

- Health
 - Mental
 - Physical
- Social
- Sensory
- **Combination**

Mental health

- Depression
- Anxiety
- OCD
- Regression syndrome
- Situational stressors
 - Grief / loss

Physical health

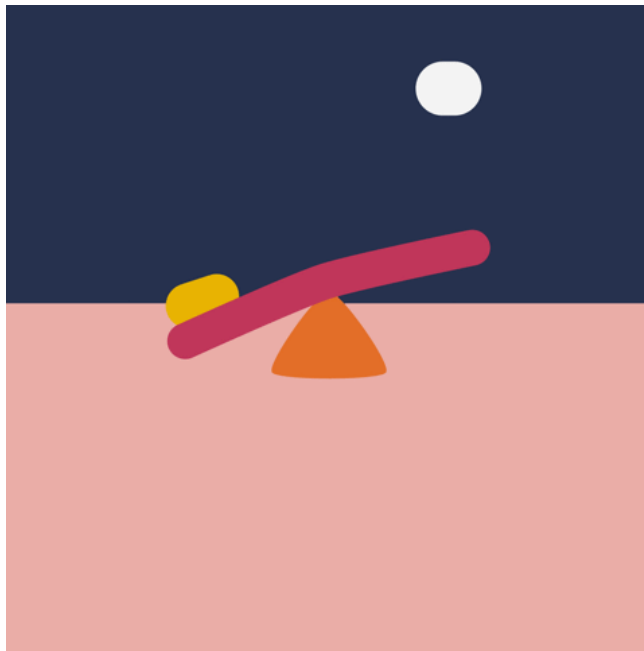
- Sleep apnea
- Vitamin B12 deficiency
- Celiac disease
- Vision or hearing impairment
- Hypothyroidism
- Pain
- Alzheimer's disease

Social

- Managing friendships and relationships
- Navigating situations at school or work
- Adjusting to changes in routine

Sensory

- 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.**



Combination

- COVID-19
 - May be impacting all 4 areas
- OCD
- Grief / loss

**How do we
address behavior
changes?**

Approach

1. Decide if the behavior change needs to be addressed
2. Talk to your health care provider.
 - Address physical and/or mental health causes
 - Interaction between mental and physical health
 - Communication challenges
3. Utilize other strategies

Strategies

- Exercise
- Healthy eating
- Psychological support
- Structure / routine
- Sensory

Exercise

- Find what works for the individual
- Fun and social
- Incorporate it throughout the day
- Go outdoors

WAYS TO BE ACTIVE!



Play a sport.



Join Special Olympics.



Join Special Rec.



Go for a jog.



Do housework/chores.



Dance.



Do an exercise video.



Stretch



Use exercise equipment.



Walk your dog.



Take the stairs.



Lift weights.

Healthy eating

- Incorporate all the food groups
- Routine for meals and snacks
- Eat with others

Tips for Eating Healthy Meals

Eat fruits and vegetables with every meal.

Starting your meal with a salad is a good way to do this.



Or fill half your plate with fruits and vegetables.



Eat whole grains.

Eat wheat bread instead of white bread.



Eat brown rice instead of white rice.



Limit condiments and dressings.

Ask for salad dressing on the side. Only use some of the dressing.



Choose grilled food instead of fried food

Eat grilled chicken or fish instead of fried or crispy chicken



Choose water or other drinks without sugar.

Drink water or unsweetened tea instead of pop/soda or sugary drinks.



Be aware of how much food you eat.

Eat your meal. Drink some water. Wait a few minutes. Go back for seconds only if you are still hungry.



Eat slowly. Put your fork down between bites of food. Or take a sip of water between bites of food.



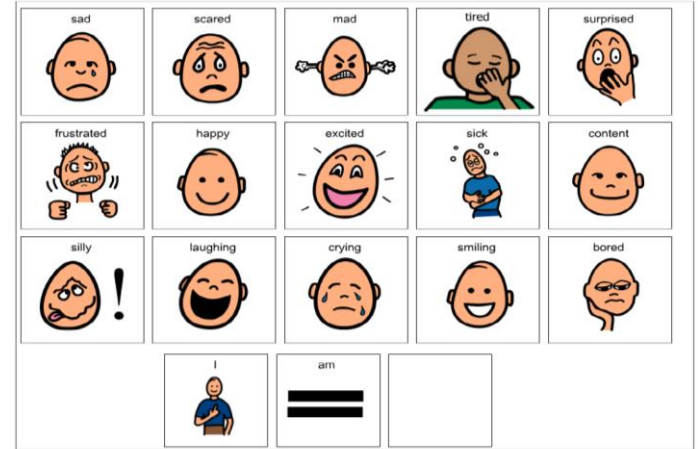
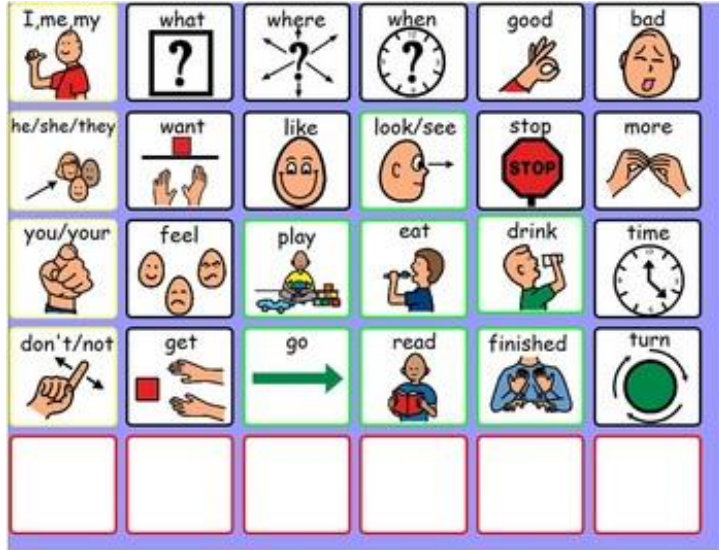
Psychological support

- Be aware of “empathy radar”
- Provide “in the moment” support when possible
- Work with a mental health provider
 - Consider therapies (e.g. music, art)

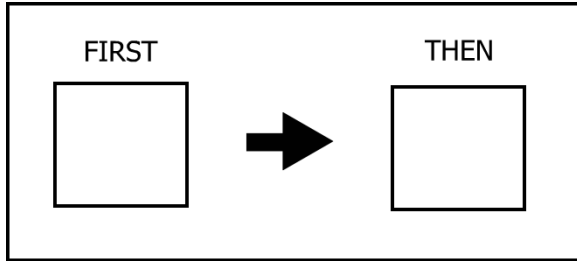
Structure / routine

- Visual supports
 - Pictures, words, or other images that are used to...
 - Help communicate
 - Share or manage expectations
 - Provide reminders
 - Teach new information
 - Facilitate understanding of challenging situations

Help communicate



Share or manage expectations

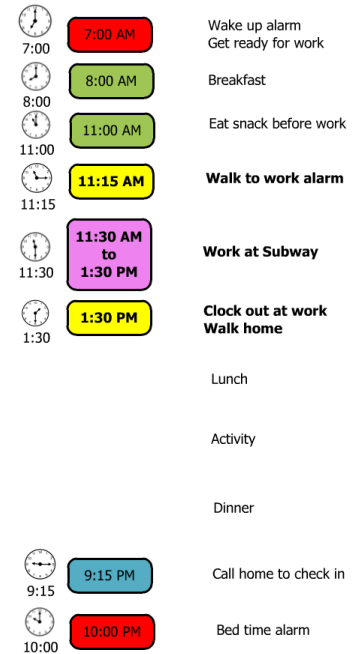


When I get frustrated...	I will ask for help.

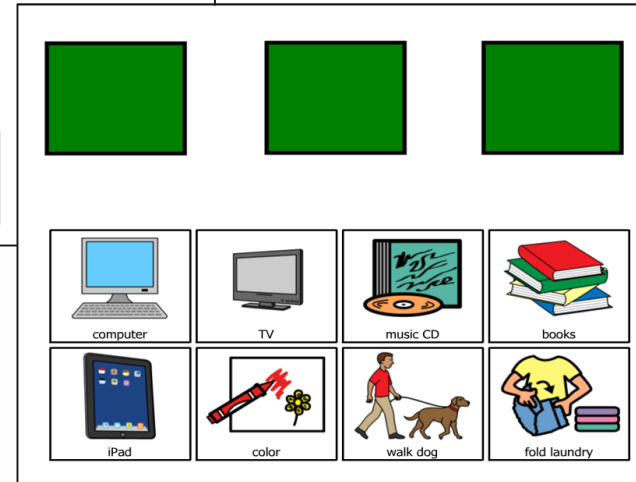
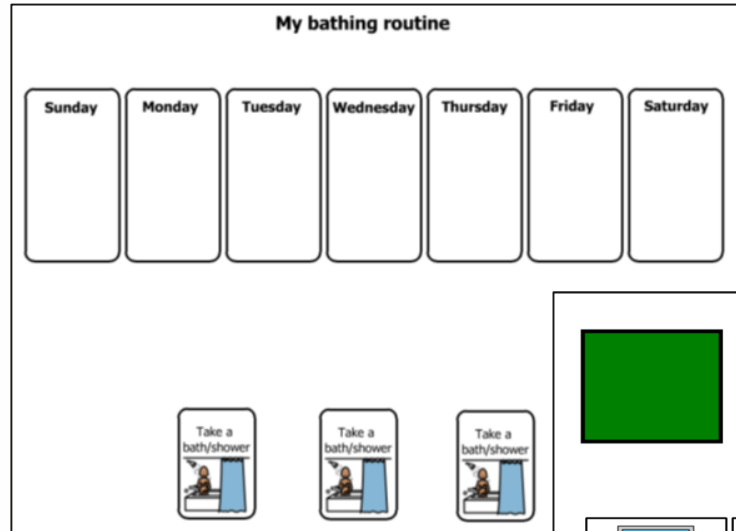
When I get frustrated...	I will do 5 pushups on the wall.



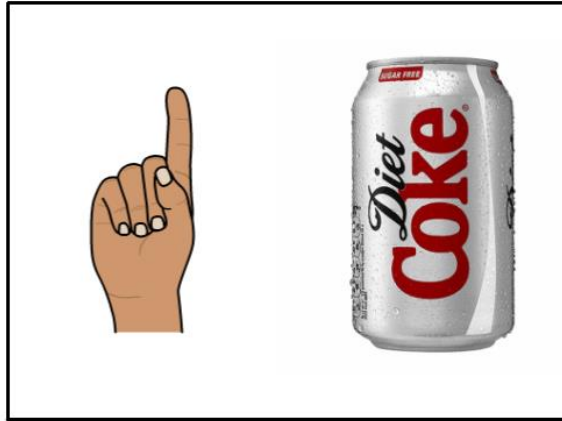
WEDNESDAY



Share or manage expectations



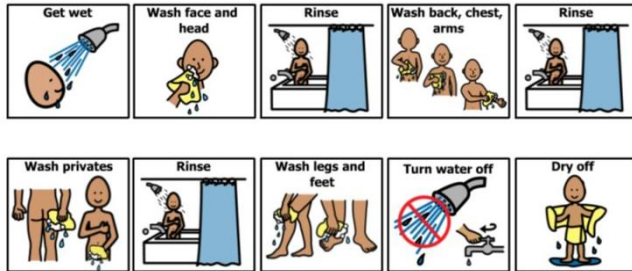
Provide reminders



Teach new information



Jericho's Shower Routine

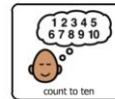


Strategies To Help Me Calm Down

CALM BREATHING



CALM THOUGHTS



CALM MUSCLES



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Advocate Medical Group
Adult Down Syndrome Center

New Way to Learn How to Tie Shoes

Tying shoes can sometimes be challenging for individuals with Down syndrome. We found this new technique that makes tying shoes a little easier!

After putting your shoe on, push the end of your laces into one of the extra holes at the top of the shoe.



Take one lace in each hand and make an X. Then loop the lace under and pull.



Facilitate understanding

Going for a sleep study



maxiSHARE

A booklet about death and funerals for people with Down's syndrome.



Let's talk about death



For more information or to obtain any of our other publications please visit www.dsscotland.org.uk

Let's Talk about the Coronavirus Video

April 2020 | Center for Autism and Related Disabilities (CARD) - University of Miami-Nova Southeastern University (UM-NSU)

Print

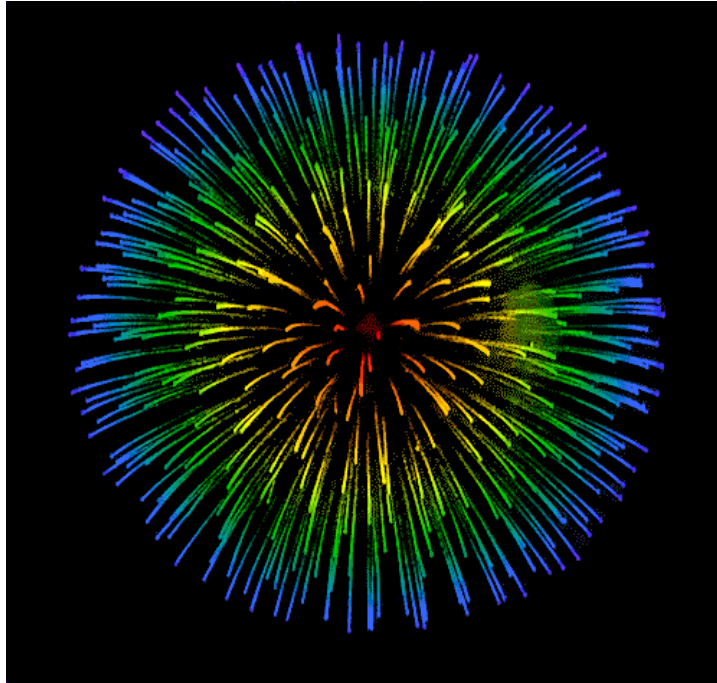
The video below uses a drawn whiteboard technique to tell a social narrative about the novel coronavirus (COVID-19). It was developed by the University of Miami-Nova Southeastern University Center for Autism and Related Disabilities (UM-NSU CARD).



Sensory

- Sensory diet
 - Accommodations
 - Activities

Sensory



Sensory diet

- A planned and scheduled activity program.
- Highly individualized.
- Choosing from a menu rather than following a recipe.
- Helps prevent sensory and emotional overload by satisfying our body's needs.

Sensory accommodations

- Used to address difficulties with sensations involving sight, sound, touch, taste, and smell.
- Examples
 - Sunglasses, dim lighting, study corral
 - Headphones (sound reducing or playing music)
 - Gloves, clothing without labels, fidgets
 - Bland foods for flavor or soft or pureed foods for texture or spicy foods and chewy or crunchy foods
 - Air purifiers, limiting perfume/lotion scents and air fresheners or aromatherapy

Sensory activities

- Used to address input to the muscles and joints
- How?
 - **Everyday activities.** See handout in resources for caregivers.
 - **Joint compression.** See handout in resources for caregivers.
 - **Affordable sensory equipment.** See handout in resources for caregivers.
- Why?
 - It can help reset a person's body and it works most of the time.

Proprioceptive Input

Many individuals with Down syndrome experience difficulty with their proprioceptive sensors in our body are responsible for providing feedback so body is in space. When these sensors aren't working like they should, some difficulty with motor coordination, meaning they appear clumsy. This could also ability to actually carry out a movement even though they know how to do it, planning. They may carry out activities and have difficulty grading their movements things too hard or too soft. Another feature is the person may have difficulty, they often appear slumped over or lethargic.

In order to activate these receptors and improve a person's proprioceptive system activities can be encouraged throughout the day to get natural input into a person's activities can be done in preparation for a transition or when you start to see a person worked up. For instance, they need to complete a series of self-care tasks in require verbal prompts to initiate the activity. Provide proprioceptive input to a person's body and prepare to complete the required task. This also goes for transitions: leave the house and your loved one with DS doesn't want to go? Try some physical input if it helps them transition. These activities may not be effective once a person melts-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-doh or clay
- Log rolling
- Vibration
- Weighted blankets
- Sitting in a beanbag
- Rocking in a rocking chair
- Strength training with light weights
- Throwing a weight
- Joint compression
- Massage
- Yard work like raking
- House work like vacuuming, washing down the counter
- Eating chewy or crunchy foods
- Sucking through a straw

Joint compression is a form of proprioceptive input. It occurs when there is compression bearing placed on a joint. It is important for developing body awareness and body stability and strength. It also promotes self-regulation and can be very calming, releasing the brain and nervous system. This is a technique that seems to be effective for individuals with Down syndrome.

It can be used to help with transitions as well as to help calm the body. Therefore, prior to an event that can be stressful for your loved one with Down syndrome, it can be used.

For any questions, please contact Katie Frank, PhD, OTR/L at 847-318-2331 or Katherine.frank@advocatehealth.com

1. Have the individual sit down in a chair or on the floor. If they want or need to, still take place.



2. Ask the individual if it is alright that you touch him/her. Once joint compression routine, you can just announce that it's time for joint compression.
3. You can start on either the right or left side and you will plan on doing joint compression on both sides.
4. Place one of your hands on top of his/her shoulder and your other hand on his/her arm, press your two hands toward one another to provide compression at the shoulder joint.



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. It is **NOT** recommended to sleep under weighted blankets.

Weighted blankets and lap pads: Prices vary, but range from \$30- \$100+ depending on size and weight.

Custom weighted blankets and lap pads:

- <http://www.sensacalm.com/weighted-blankets/>
- <http://www.mosaicweightedblankets.com/> (they even offer DIY kits)
- Amazon, Bed Bath & Beyond, and Etsy even carry weighted products

Weighted snake: Prices range from \$25 - \$50+

Amazon has a few versions. They vary in weight.



Alternative ideas to expensive weighted objects

- Door stoppers and neck wraps and warmers (priced \$10 and up)



- Available at drug stores and websites like Amazon. Bed Bath and Beyond and Amazon carry a brand called Bed Buddy.
- Talk with your dentist as you may be able to get an old lead vest used for x-rays.

Vibrating products:

- **Hand held massager:** Amazon as well as drug stores, Target, WalMart etc. (priced

under \$10)



- **Vibrating cushion:** Amazon carries a brand by Dr.Scholl's (priced under \$30)



or vibrating cushion



- **Vibrating neck massager** (priced \$20- \$50)



D

Some Sleep Tight Weighted Blankets provide deep pressure which promotes relaxation and a restful night sleep.

- Gentle pressure of weighted blankets provides the same experience as swaddling
- 100% Cotton
- Polyester insert filled with glass or plastic pellets
- Suitable for all ages
- 5 lb. blanket fits users 2' 6" - 3' 0" x 36"
- 8 lb. blanket fits users 3' 0" - 3' 6" x 42"
- 12 lb. blanket fits users 3' 6" - 4' 0" x 54"
- 16 lb. blanket fits users 4' 0" - 4' 6" x 60"
- 25 lb. blanket fits users 5' 0" - 6' 0" x 84"
- Machine washable
- Made from 100% cotton and imported materials

Only Sleep Tight Weighted Blanket So

Example from the Clinic

- Presented with non-compliant behavior at home but not at day program
- Identified mental health diagnosis and treated with medication
- Utilized visual supports to establish structure and routine at home

Example from the Clinic

- Presented with a change in sleep habits
- Addressed physical and mental health causes but no medications or treatments indicated
- Utilized visual supports and sensory strategies

Example from the Clinic

- Presented with mental health concerns
- Identified physical cause and prescribed treatment
- Utilized visual supports to improve compliance

Questions?

Contact us

adsresources.advocatehealth.com/contact