Behavior Change in Individuals with Down Syndrome

Empowering Every Stage Conference
Down Syndrome Connection of the Bay Area

September 12, 2026 | Katie Frank, PhD, OTR/L

Advocate Health Care®


Advocate
Medical
Group
Adult Down
Syndrome Center
1610 Luther Lane

Disclaimer

- This presentation is meant to support families, caregivers, and professionals who care about and for individuals with Down syndrome.
- The information shared today is for learning and discussion, not to replace medical or therapeutic care.
- Everyone is different. If you have questions specifically about your loved one, you are encouraged to talk to their doctor or therapist.
- Neither ADSC staff nor Advocate Health endorse any products discussed in this presentation.
- AI was NOT used for any portion of this presentation.

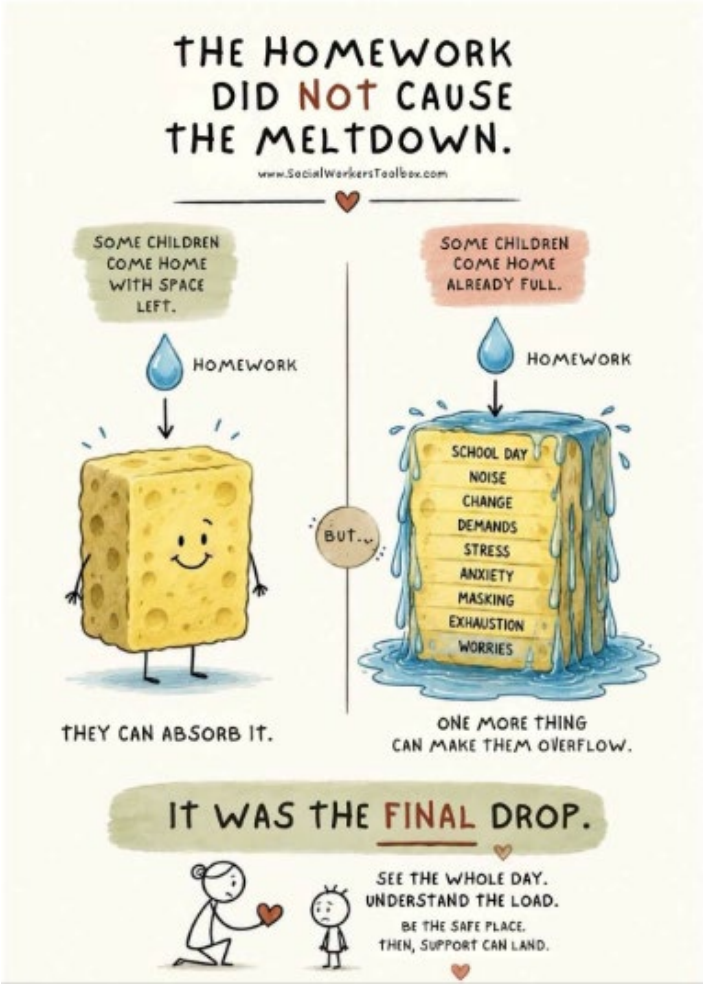
Today’s agenda

- Identify common behavioral challenges that may impact participation and independence in individuals with Down syndrome.
- Understand the underlying causes and functions of behavior, including how to assess and interpret behavior changes effectively.
- Apply practical strategies to support positive behavior, such as techniques for managing transitions, maintaining attention, and encouraging participation.

Behavior

What is behavior?

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



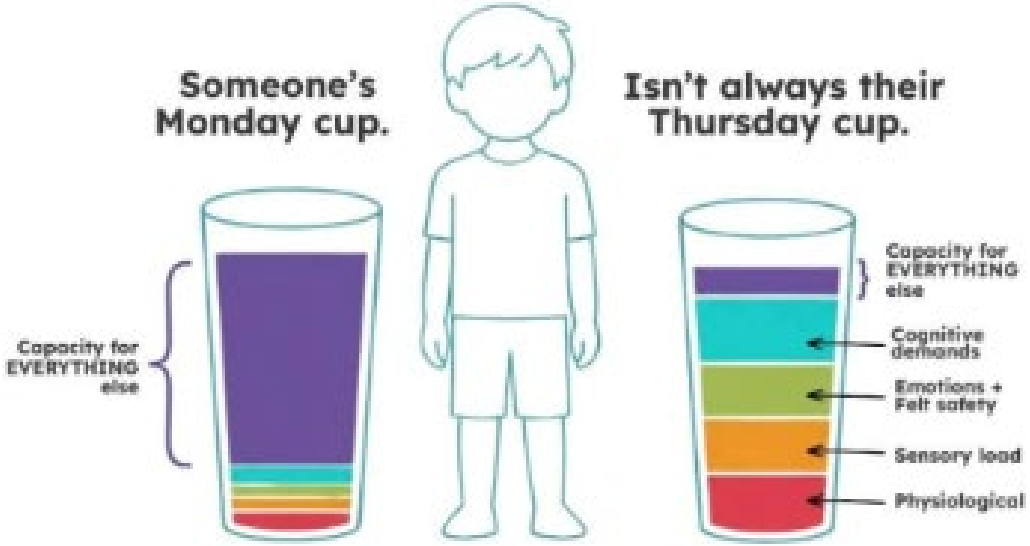
Examples of behavior challenges

- Change in self-talk
- Exhibiting obsessive-compulsive behaviors
- Stubbornness/oppositional behavior
- Agitation or aggression
- Regression of skills
- Impulsivity
- Self-stimulatory behaviors
- Tantrums or meltdowns
- Wandering off
- Difficulty following changes to routine
- Short attention span
- Anxiety
- Sadness
- Avoidance
- Poor boundaries

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

Fluctuating Capacity

Why the same kid can do something one day and not the next



The skill didn't change. Their capacity did.

thinksensory

What can cause problematic behavior?

Causes of problematic behavior

- Health
- Sensory
- Social/Environmental

Health causes

- Sleep apnea
- Vitamin B12 deficiency
- Celiac disease or other GI issues
- Vision or hearing impairment
- Hypothyroidism
- Mental health (depression, anxiety, OCD)
- Pain
- Seizures/neurological conditions
- Alzheimer’s disease

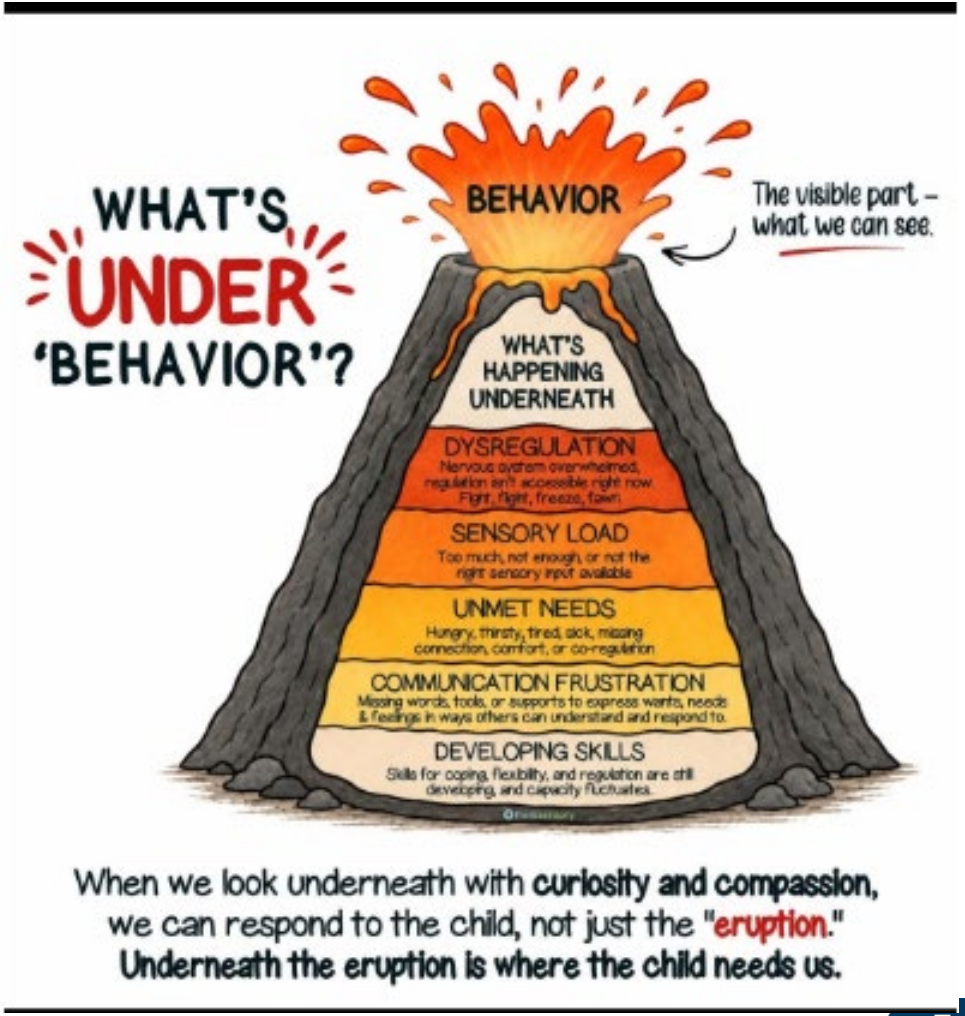
Sensory causes

- 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.
- Grief
- Life stressors or changes.

How do we address problematic behavior?



When we look underneath with **curiosity and compassion,**
we can respond to the child, not just the "**eruption.**"
Underneath the eruption is where the child needs us.

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?

Talk to a health care provider.

What is the individual trying to communicate?

- Needs, desires, challenges

Strategies

Health

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

Non-medicinal / non-health

- Sensory
- Structure / routine
- Social supports

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.
- 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.
  - Tone, speed, volume, body language
- 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

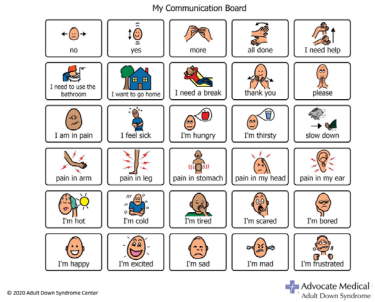
- Encourage the person in a way that lets him/her know that he/she is exhibiting the desired behavior
  - Use specific language rather than "good job"
- Be enthusiastic and generous with encouragement and praise.
- Be strategic and cautious with consequences and/or punishment.
- Stick with it. Be consistent.

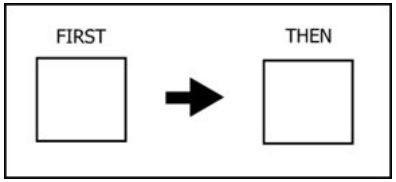
Offer choices

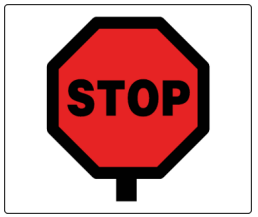
- Provides a sense of control.
- Reduces the power struggle.
- Good if they are looking for access to an item or activity.
- Example:
  - You need to shower today; do you want to do it now or after dinner?
  - It is time to go; do you want to listen to music or watch videos in the car?

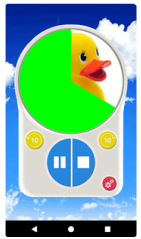
Use visuals and reminders

- Make expectations clear.
- Helps with predictability and to provide structure and routine.
- Can provide reminders.
- Contract between the caregiver and the individual.
- Limits the need to process instructions auditorily.
- Provides a way to communicate when body is dysregulated.









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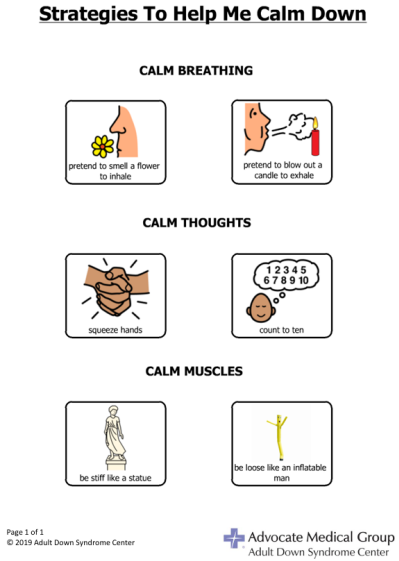
Teach and practice calming strategies

- Breathing activities
- Counting to 10
- Wall push-ups
- Squeeze a stress ball
- Talk a walk
- Listen to music



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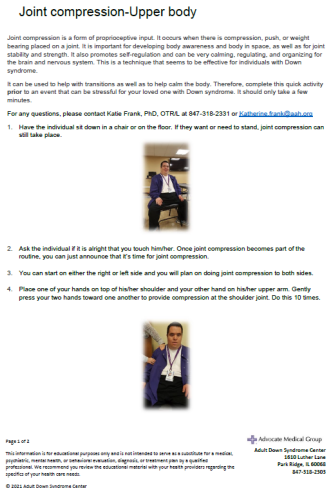
Provide movement breaks/Create a calm space

- Helps reset the sensory system, which is impacted when someone becomes dysregulated
- A safe place to help regulate and reset
  - Room, basement, bathroom
- Examples
  - Sensory accommodations
  - Sensory activities
  - Sensory toolkit with other calming activities



Joint compression-Upper body

Joint compression is a form of proprioceptive input. It occurs when there is compression, push, or weight bearing placed on a joint. It is important for developing body awareness and body in space, as well as for joint stability and strength. It also promotes self-regulation and can be very calming, regulating, and organizing for 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, complete this quick activity prior to an event that can be stressful for your loved one with Down syndrome. It should only take a few minutes.

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

2. Ask the individual if it is alright that you touch him/her. Once joint compression becomes part of the 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 to both sides.
4. Place one of your hands on top of his/her shoulder and your other hand on his/her upper arm. Gently press your two hands toward one another to provide compression at the shoulder joint. Do this 10 times.

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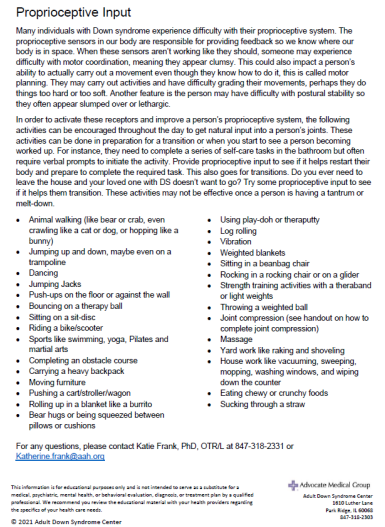

Proprioceptive Input

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

In order to activate these receptors and improve a person's proprioceptive system, the following activities can be encouraged throughout the day to get natural input into a person's joints. These activities can be done in preparation for a transition or when you start to see a person becoming worked up. For instance, they need to complete a series of self-care tasks in the bathroom but often require verbal prompts to initiate the activity. Provide proprioceptive input to see if it helps restart their body and prepare to complete the required task. This also goes for transitions. Do you ever need to leave the house and your loved one with DS doesn't want to go? Try some proprioceptive input to see if it helps them transition. These activities may not be effective once a person is having a tantrum or 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-doh or theraputty
- Log rolling
- Vibration
- Weighted blankets
- Sitting in a beanbag chair
- Rocking in a rocking chair or on a glider
- Strength training activities with a theraband or light weights
- Throwing a weighted ball
- Joint compression (see handout on how to complete joint compression)
- Massage
- Yard work like raking and shoveling
- House work like vacuuming, sweeping, mopping, washing windows, and wiping down the counter
- Eating chewy or crunchy foods
- Sucking through a straw

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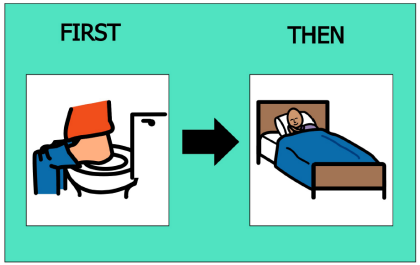
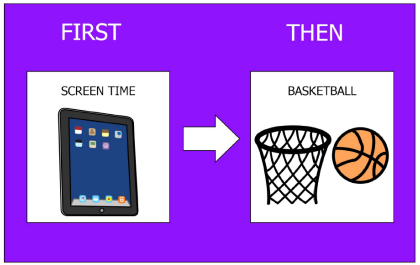
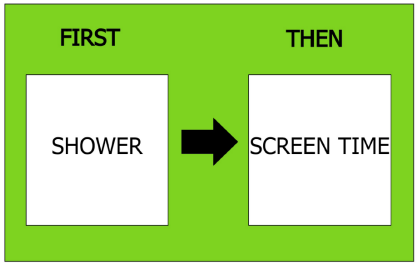
Use first/then language

- Helps with expectations.
- Simplifies instructions.
- First is the non-preferred task and then is the preferred task.
- First is the thing that needs to happen and the then is the next, even if it isn’t a break.
- Can be used for any function of behavior.







Reduce wait time and transitions

- Transitions are hard
  - Provide warnings
    - Do not use too many words or give too many steps
    - Allow time to process
  - Use timers
  - Provide a transition activity
  - Use first/then
- Good for escape behaviors or attention seeking or avoiding, even sensory

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

Is it sensory or behavior?

Observed "behavior"	Unmet need	Possible response
Yelling, hitting, throwing	Emotional overload, lack of coping skills, sensory distress, communication	Offer a break, provide sensory activities, calm down tools, visuals
Walking out or hiding	Anxiety, fear of failure, overstimulation	Ensure safety, offer space, provide sensory activities
Refusal	Something is too hard, not meaningful, or fear being wrong, anxiety, confusion, sensory overload	Break task down into smaller steps, offer choices, celebrate effort, clear expectations
Constant interruptions	Impulsive, need for connection, difficulty self-regulating	Offer movement breaks, use visual supports, validate engagement
Shutting down or zoning out	Cognitive overload, trauma response, fatigue, anxiety	Reduce sensory input, offer a break
Aggression toward peers	Lack of social cues, emotional dysregulation, difficulty communicating	Offer space, teach social skills, label emotions, offer sensory activities, visuals

Things to avoid

- Long lectures or even just using too many words.
- Correcting in public-remember the behavior is often not on purpose.
- Removing all breaks or opportunities for sensory.
- Having too high of expectations.
- Ignoring early warning signs.

Case examples

Case 1

You are at Target with your loved one and seemingly out of no where, they run and hide under clothing display.

Why could this have happened?

What can you do to resolve the situation?

Case 2

A participant is at Special Olympics. They are laying all over the floor and touching the other participants without respecting personal space. They are constantly interrupting and making lots of silly sounds to be disruptive.

Why could this have happened?

What can you do to resolve the situation?

Case 3

You are at a restaurant. Your loved one just start crying and won’t stop. You don’t know what to do and don’t want to interrupt the other patrons. You want to leave but aren’t sure how to get your loved one out of the building.

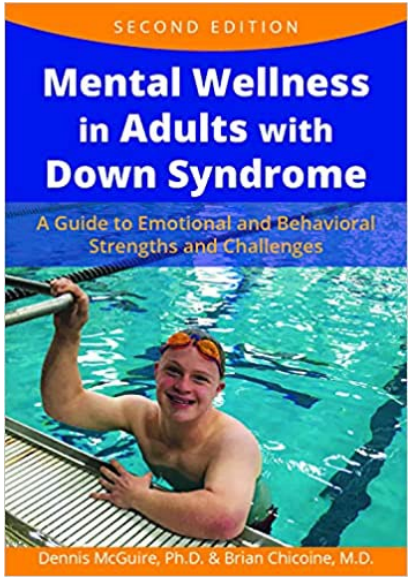
Why could this have happened?

What can you do to resolve this situation?

Things to remember

- Behaviors happen. The question is to ask yourself whether the behavior *needs* to change.
- Rule out medical causes for behaviors.
- Be firm and set guidelines.
- Make sure the intervention matches the function.
- Manage expectations by telling the person what you want them to do.
- Use visual supports to support positive behaviors.
- Offer choices.
- Set boundaries.
- BE CONSISTENT ACROSS ENVIRONMENTS AND CAREGIVERS.

Free copy of the Mental Wellness book



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

Questions?

Resource Library

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Email List

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