

POSITIVE BEHAVIOR STRATEGIES TO SUPPORT INDIVIDUALS WITH DOWN SYNDROME ACROSS THE LIFESPAN

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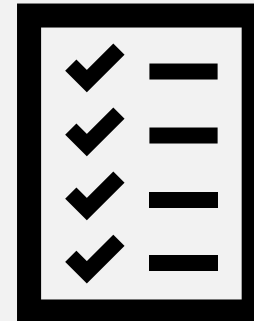
Waisman Center

12 March 2022



AGENDA

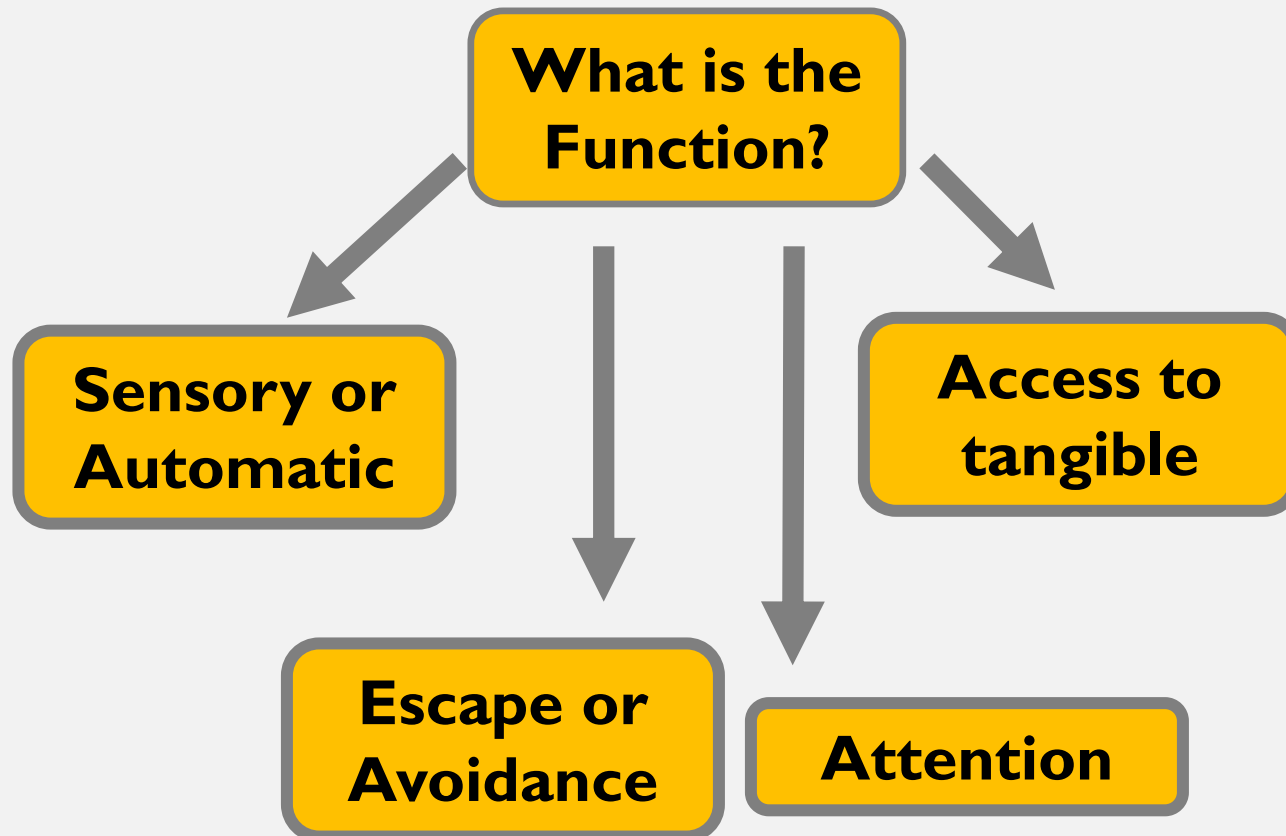
- Discuss and define behavior
- Assessment of behavior
- Prevention strategies
- Intervention strategies
- Resources & support



BEHAVIOR

- What is the behavior?
 - Important to define the behavior using specific terms – throwing food or kicking with foot vs “outburst” or “meltdown” or “aggressive”
- Common behavior concerns in DS (National Down Syndrome Society, 2022; Stein, 2016):
 - Wandering/elopement
 - Task refusal/”stop and flop” behavior
 - Physical aggression
 - Self-stimulatory behaviors
 - Insistence on sameness
 - Problems with boundaries

BEHAVIOR = COMMUNICATION



Important!

- Need to examine and rule out any underlying medical causes
- Response to pain, discomfort, or illness?
- Significant sleep concerns?
- *Especially with new or worsening behaviors

ABC'S OF BEHAVIOR

- **A** = Antecedent
 - Event that comes before a behavior
- **B** = Behavior
- **C** = Consequence
 - Event that follows a behavior

Antecedent

Behavior

Consequence

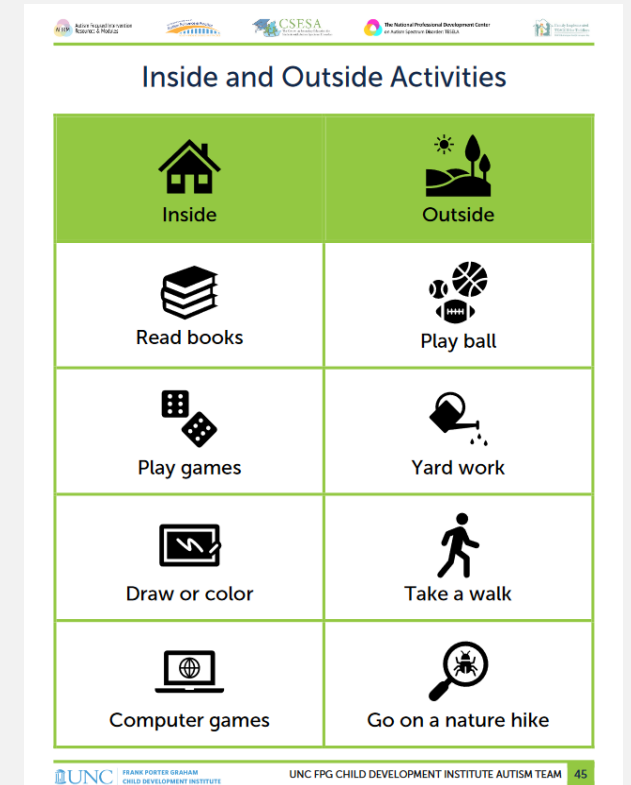
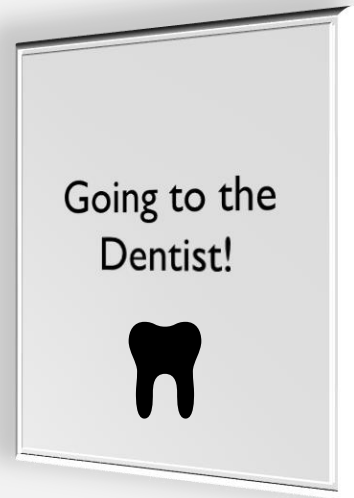
Date/Time Setting	Antecedent Description of the environment and what occurred prior to the behavior	Behavior What the child did or said and how long the behavior lasted	Consequence What the responder did immediately following the behavior or how the environment changed

PREVENTION STRATEGIES

Use visual and/or auditory cues	Arrange the environment	Do things in small doses	Change order of events
Respond to early signs of the problem	Change how you ask or respond	Address setting events (illness, hunger, sleep)	Create a routine where there isn't one

VISUALS!

- Visual schedules
- Visual choice boards
- Visual timers
- Social stories
- Video modeling



Source: UNC Frank Porter Graham Child Development Institute Autism Team

VISUAL SCHEDULES

Daily Schedule Example

Task	Done
Wake Up	
Brush Teeth	
Get Dressed	
Eat Breakfast	
Read (30 minutes)	
Exercise (30 minutes)	

* Note: Icons from Microsoft Word Icons (Insert tab)

FRANK PORTER GRAHAM CHILD DEVELOPMENT INSTITUTE UNC FPG CHILD DEVELOPMENT INSTITUTE AUTISM TEAM 40



Create Visual Supports for your child

Select a template

1 image/page

2 images/page

4 images/page

6 images/page

12 images/page

16 images/page

Let's get started

The visuals engine will help you build visual supports and sequences for your child.

Steps:

1. Select the template with the size of picture you want.
2. Select a picture to put in the template.
3. Type in the title you will use for that picture.
4. Repeat for more pictures.

Now you are ready to print and use!

Different uses

The list below will give you tips on the different ways visuals can be used and examples of the recommended sizes for each type of visual:

- Choice Boards
- Circle Time Boards



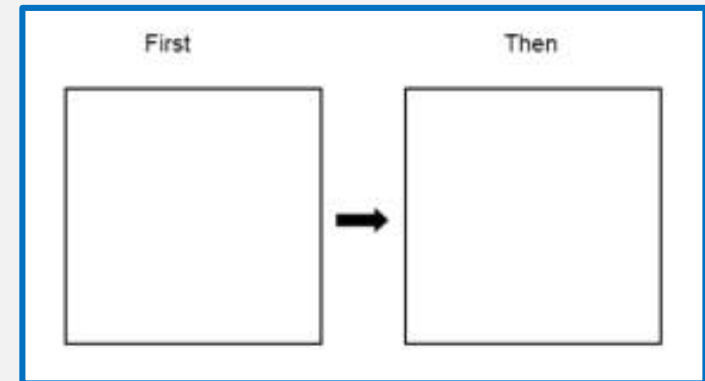
Sources: UNC Frank Porter Graham Child Development Institute Autism Team, <https://connectability.ca/visuals-engine/>, and Stein, 2016

SPECIAL TOGETHER TIME

- Set aside 5-10 minutes with just you and your child/teen/adult (use a timer!)
- Have your loved one choose an activity they'd like to do, with you observing or participating (ideally not electronics)
- You can imitate (e.g., start drawing on your own paper if they are drawing, build with your own playdoh or kinetic sand, use your own Legos, etc)
- Make neutral or positive comments (imagine you are like a sportscaster)
 - Neutral: "You are making a tower," or "You are drawing Squirtle"
 - Positive: "I love how you _____," or "That's a great _____," or "How neat/cool!"
- Refrain from asking many questions or giving directions/reprimands
- Try to end on a good note – using a timer can be helpful for this. Ignore minor misbehavior and end the together time if the behavior becomes too disruptive, letting them know you can do this again later.

DIFFICULTY WITH TRANSITIONS

- First/then language
- Pair preferred and nonpreferred activities
- HighP (high probability) requests



CONSEQUENCE STRATEGIES



- Reinforcement
 - Something the individual will work to earn
 - Can vary! Might include hugs, high-fives, praise, sticker, a small toy, food, drink, allowance, or special activity
 - Token systems – individual can earn points, stars, stickers, etc that are later used to "cash in" for a bigger reward

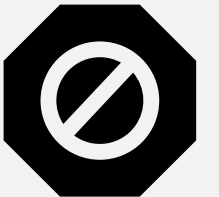
CONSEQUENCE STRATEGIES CONT'D



- To consider on occasion and in specific circumstances: Planned ignoring
 - For some behaviors that have an attention function and do *not* involve safety concerns, planned ignoring can be selectively used – this involves withholding your voice, eye contact, facial expressions, and physical touch for inappropriate ways to get your attention and then giving *lots* of attention for appropriate ways of doing so
 - Again, reinforcement of appropriate behaviors is where we want to focus whenever possible!

BOLTING/ELOPEMENT

- What not to do:
 - Get upset, give lots of eye contact or strong facial expressions, yell, lecture
- What to do
 - When your loved one is running away
 - Keep everyone safe. BUT – keep your reactions in check.
 - Hold the individual's hand or arm, get them to safety, and gently state “No running.”
 - Before your loved one runs away
 - In the home: safety locks they cant reach, alarms on doors and windows, visual supports such as stop signs, GPS systems, consider contacting local police dept and neighbors before anything happens
 - Think about structures and safeguards to put in place, such as teaching a child to hold hands or do another behavior that is incompatible with running. Practice during low risk scenarios, and/or use a social story.
 - Build a structure – such as a motivator. First walk, then iPad.



SENSORY/SELF-STIMULATORY BEHAVIORS

- If not causing harm to themselves/others and not significantly interfering with daily life – may not need to intervene at all!
- Can help establish boundaries if needed (e.g., private behaviors in the bedroom or bathroom with door closed)
- Can work with an occupational therapist (OT) to help provide appropriate replacement behaviors if needed and then reinforce use of those replacement behaviors

RESOURCES

- “Supporting Positive Behavior in Children and Teens with Down Syndrome: The Respond but Don’t React Method” by David Stein, Psy.D. (2016)
- Social stories: <https://carolgraysocialstories.com/social-stories/what-is-it/>
- More on video modeling and DS & autism: <https://www.waisman.wisc.edu/outreach/waisman-center-day-with-experts/down-syndrome-day-with-the-experts-document-and-video-archive/#2019>
- Visual Creator: <https://connectability.ca/visuals-engine/>
- UNC Frank Porter Graham Child Development Institute Autism Team's Resource on Supporting Individuals with Autism Through Difficult Times <https://aahd.us/wp-content/uploads/2020/04/Supporting-Individuals-with-Autism.pdf> (written for individuals with autism but also really helpful for individuals with DS who do not have autism)
- Vanderbilt Healthy Bodies Toolkit (includes visuals related to public/private behaviors): <https://vkc.vumc.org/healthybodies/>
- Waisman Center Down Syndrome Hub: <https://www.waisman.wisc.edu/outreach/ds-hub/>

FOR MORE SUPPORT

- CLTS case manager/Family Care Service Coordinator/IRIS consultant
- Primary care provider
- For school-age children – your child’s school team
- Outpatient speech-language or occupational therapists
- Mental health clinician with experience with DS or other DD
- Psychiatry
- Applied behavior analysis therapy or consultation
- Wisconsin Regional Centers Children and Youth with Special Health Care Needs (CYSHCN) <https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>
- Aging and Disability Resource Center (ADRC) <https://www.dhs.wisconsin.gov/adrc/index.htm>

REFERENCES

- Bearss, K., Johnson, C., Handen, B., Butter, E., Lecavalier, L., Smith, T., & Scahill L. (2015). *RUBI autism network: Parent training for disruptive behavior [a treatment manual]*. Publisher: Authors.
- National Down Syndrome Society. (2022). Managing Behavior. Retrieved from: <https://www.ndss.org/resources/managing-behavior/>
- Stein, D. (2016). Supporting positive behavior in children and teens with Down syndrome: The respond but don't react method. Woodbine House: Bethesda, MD.

QUESTIONS?