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

Martha Walter, PhD
Psychologist & Co-Director, Down Syndrome Clinic
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

What is the Function?

- Sensory or Automatic
- Access to tangible

Escape or Avoidance

Attention

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
| 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 |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Prevention Strategies

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

Bearss, Johnson, Handen, Butter, Lecavalier, Smith, and Scahill, 2015
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

<table>
<thead>
<tr>
<th>Task</th>
<th>Done</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wake Up</td>
<td></td>
</tr>
<tr>
<td>Brush Teeth</td>
<td></td>
</tr>
<tr>
<td>Get Dressed</td>
<td></td>
</tr>
<tr>
<td>Eat Breakfast</td>
<td></td>
</tr>
<tr>
<td>Read (30 minutes)</td>
<td></td>
</tr>
<tr>
<td>Exercise (30 minutes)</td>
<td></td>
</tr>
</tbody>
</table>

*Note: Icons from Microsoft Word Icon Browser*

Create Visual Supports for your child

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
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!
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 can’t 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

- Social stories: https://carolgraysocialstories.com/social-stories/what-is-it/
- Visual Creator: https://connectability.ca/visuals-engine/
- 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](https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm)
- Aging and Disability Resource Center (ADRC) [https://www.dhs.wisconsin.gov/adrc/index.htm](https://www.dhs.wisconsin.gov/adrc/index.htm)
REFERENCES


QUESTIONS?