NAVIGATING BEHAVIOR

national down syndrome society ndss

UC Health

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Executive Summary

Individuals with Down syndrome, like all people, use behavior as a form of communication. When internal needs, emotions, or discomfort cannot be effectively expressed, behaviors may emerge that disrupt daily routines.

This guide provides parents, families, and caregivers with a practical framework for understanding and addressing challenging behaviors in individuals with Down syndrome. It outlines the underlying causes of behavior, emphasizes the importance of interpreting behavior as communication, and offers evidence-informed strategies for prevention, intervention, and long-term support. By shifting the focus from managing behavior to understanding its function, caregivers can promote more effective communication, strengthen relationships, and improve overall quality of life.

Introduction

Individuals with Down syndrome, like anyone, use outward behaviors to communicate internal needs or feelings. Challenges with communication, limited vocabulary to explain internal states, and communication partners who may not know the person well, can all contribute to the development of behaviors that are disruptive to daily life, also called maladaptive behaviors. This guide is designed help families, caregivers, and professionals of individuals with Down syndrome understand the reasons challenging behaviors occur and provide direction on interventions.

This resource is not a substitute for collaborating with qualified professionals in your area to understand and develop interventions. There are some challenging behaviors and situations that demand immediate response from emergency services. If there is an immediate risk of harm to the individual with Down syndrome or others, first responders or crisis services are recommended. If the situation requires additional support services, caregivers should mention that the individual has Down syndrome and provide any relevant details to help first responders interact with the individual with Down syndrome.

How do we understand challenging behavior?

All behavior is understood to have root causes and factors that maintain the behavior. These are known as the 'function' of the behavior. Common functions of behavior include medical problems, escaping from demands, gaining attention, sensory challenges, and access to tangible items. As we learn more about the trauma experiences of individuals with Down syndrome, it is becoming clear that some behaviors are related to previous traumas; particularly if the situation causes the individual with Down syndrome to feel like they did at the time the trauma occurred. It is important to keep data on the challenging behavior to show patterns that will help determine function. Some individuals with Down syndrome may engage in multiple challenging behaviors, so it is important to carefully define the behavior you are targeting. The same process is used regardless of the type of behavior, but it is suggested that only one behavior be targeted at a time. Similar behaviors can have distinct functions in different environments, so accurate data collection is important to truly understand challenging behavior.

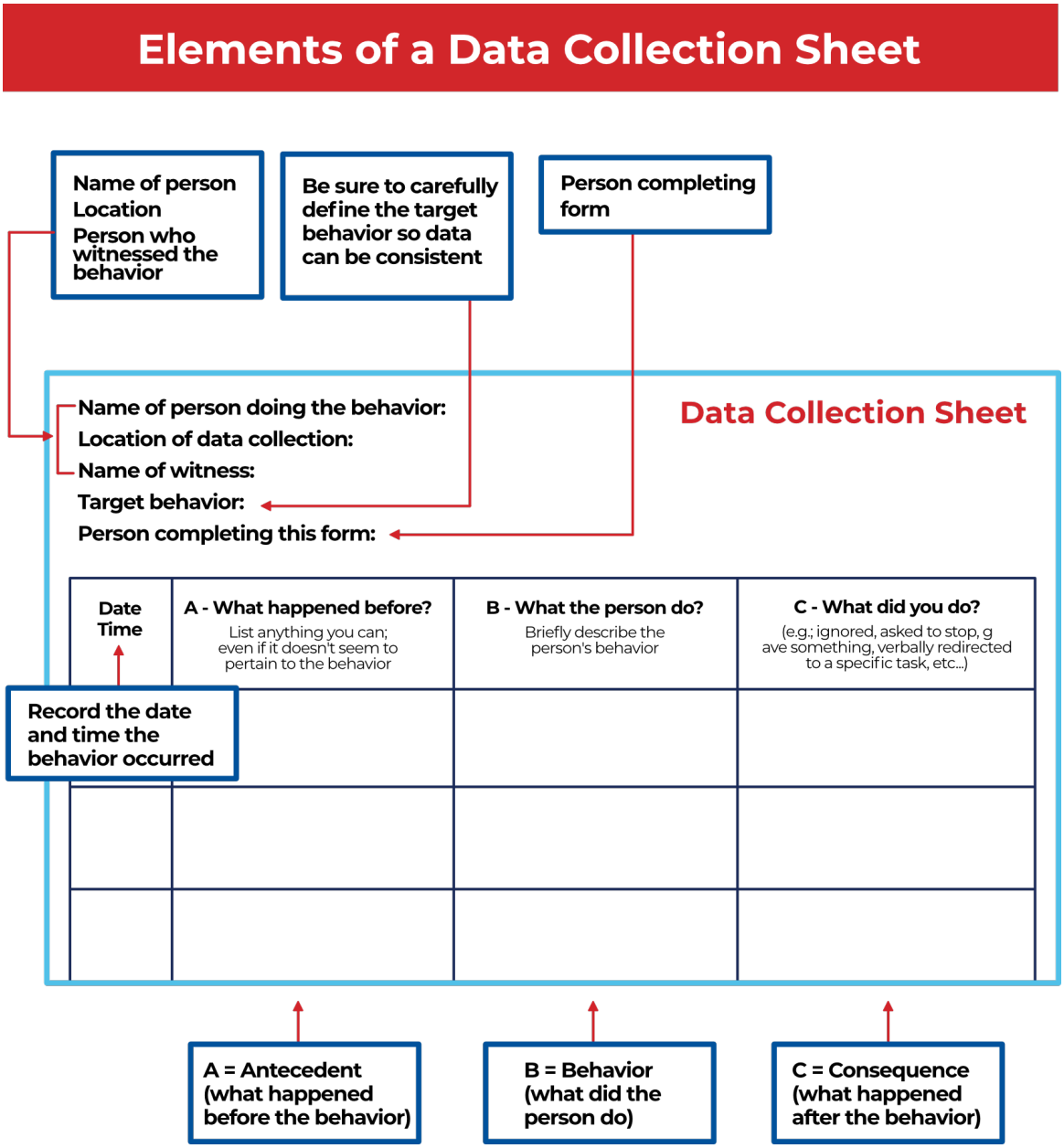
The following checklists can help think through the root causes of behavior.

Behavior Checklist

Describe the behavior in as much detail as possible:

- [ ] What is the behavior, what does it look like?
- [ ] How often does it happen?
- [ ] Where does it happen?
- [ ] When does it happen?
- [ ] What is going on in the environment when the behavior happens?
- [ ] Who does the behavior happen with (family, staff, teachers, etc.)?

This type of data is often collected using an A-B-C data sheet. This data looks at the Antecedent (what happened before the behavior occurred), the Behavior (description of the target behavior), and the Consequence (what happened after the behavior occurred) to determine patterns of the behavior. Below is an example of an A-B-C data sheet. There are other ways of gathering this information, but the example below shows all the essential elements of data collection. A full-size, fillable A-B-C data collection sheet is available at the end of this guide.



It can be helpful to think through some root causes of challenging behaviors.

Do any of the following issues explain the current challenging behavior?

- ☐ Communication concerns (is the person able to tell you what is wrong? Could they use pictures or other communication devices to help tell you what they are feeling)?
- ☐ Ongoing medical concerns (could any medical concerns be worse? Gastro-intestinal issues, dental problems, sleep concerns, etc.)?
- ☐ Physical pain (be sure to consider and rule out physical pain, including dental pain, as the reason behind any behavior that might be new or unusual)?
- ☐ Medication side effects (any recent medication changes, dosing changes, missed medications)?
- ☐ Recent losses (grief reactions, trauma anniversaries)?
- ☐ Recent changes in routine/structure of the person's typical day or activities (are there unfamiliar staff or people supporting the person; did they have to do something out of the ordinary or unpredictable, have they recently moved or changed day programs, etc.)?

Also, based on the age of the person with Down syndrome, we should also consider the following:

For *children* with Down syndrome:

- ☐ Problems/changes to routine or activities at school?
- ☐ Problems with peers?
- ☐ Problems with siblings/family?

For *adolescents* with Down syndrome:

- [ ] If female, have they recently started their period or could they have period pain?
- [ ] Growing pains, weight gain?
- [ ] Starting or going through puberty?
- [ ] Problems at school or changes to routine or activities?
- [ ] Problems with peers?
- [ ] Problems with siblings/family?

For *adults* with Down syndrome:

- [ ] Problems or changes to routine or activities at work or day programming?
- [ ] Problems with or changes in direct care staff?
- [ ] Changes in relationships with friends or family?

For *older adults* with Down syndrome:

- [ ] Is the person showing signs of cognitive decline? Visit the NTG-EDSD Screening Tool | Dementia and ID or DD | The NTG for specific behaviors to monitor. (https://www.the-ntg.org/ntg-edsd)
- [ ] Problems with or changes to routine or activities at work or day programming?
- [ ] Problems with or changes in direct care staff?
- [ ] Recent losses of friends or family?

How do we intervene with challenging behavior?

Important note* - Interventions for challenging behavior may initially make the behavior worse. This is because the behavior was the best way for the person to get their needs met, and when that is taken away, they may initially try to engage in more behavior to get to the same end. Only consistent interventions can help the person learn that the behavior does not work as well as the intervention does to meet their needs. Any suggestions in this document should serve as a guide to best practices, not as an individualized treatment plan. Interventions should be reviewed with local doctors or specialists to help determine whether they are appropriate to use in the long term.

Once we understand why challenging behavior occurs, we can design interventions. Any intervention should aim to serve the same function as the target behavior. For example, if a person engages in challenging behavior to get attention, interventions should provide the person with a safer way of getting attention. Possible interventions could be teaching the person to ask for attention, raise their hand, or use another communication system to make the request for attention. Over time, interventions that work well should be adapted so they can be used easily in all settings. The suggestions below can help guide you toward the best interventions based on the function of the target behavior. We will start with some common suggestions and then talk in more detail about some specific behaviors that pose more risk.

Common Interventions Based on the Function of the Challenging Behavior

For behaviors with a *medical* function:

Attempt to determine what the medical issue is by contacting physicians or mental health professionals

- ☐ Keep careful notes about what the issue looks like and how often it is happening
- ☐ Offer support to ease pain or discomfort as appropriate
- ☐ Consider any recent medication changes or side effects from routine medications

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For behaviors with an *escape* function:

- ☐ Offer a safe way to get away such as offering a quiet space for the person to self-calm
- ☐ Allow the person to take a break, then return to their expectations after a set amount of time (consider setting a timer or using visual supports to let the person know how long the break will be)

For behaviors with an *attention-seeking* function:

- ☐ Plan for regular time to give positive attention in a one-on-one setting (consider reading a book together every night before bed; schedule 20 minutes every day at a designated time to give undivided attention to the person)
- ☐ Catch the person being good and offer positive praise for safe actions and desirable behaviors
- ☐ Let the person know when you will spend one-on-one time with them (and follow through)

For behaviors with an *access to tangible items* function:

- [ ] Let the person know when they can access that object (or person, or activity)
- [ ] Use a visual schedule to show when that object (or person, or activity) will be available
- [ ] Offer a similar alternative when the desired item is not available right away (for example, always offer easily accessible healthy snacks to help with waiting for mealtimes)

For behaviors related to *previous trauma*:

- [ ] Learn as much as possible about the person's trauma history; look for patterns of behavior that were used for survival during those times and whether the current behaviors are similar
- [ ] Remind the person that you are a safe person and are there to help; use language that communicates they are in control while you are there to provide what they need; say things like "I want this to be a safe space for you"
- [ ] Offer empathy, recognize the person's survivorship, and thank them for sharing their history with you

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For behaviors with a *sensory* function:

- [ ] Notice what type of sensory stimuli person seeks or avoids; consider all 8 senses: sight, touch, taste, smell, sound, proprioception (where the body is in space), interoception (internal sensations), and vestibular (balance)
- [ ] If the person is seeking certain sensory input, provide access to sensory supports that match what is being sought such as a swing, weighted blanket, scent kit, squishy toys, etc.

- ☐ The person can have some senses that are over-sensitive while other senses may be under-sensitive
- ☐ If the person is avoiding certain sensory input, provide a way to avoid unpleasant sensory inputs such as sound blocking headphones, sunglasses, or loose clothing

Additional Considerations for Specific Challenging Behaviors

As noted above, it is important to remember interventions can initially make behaviors worse.

For *self-injury* and *self-harm*:

As noted above, interventions can initially make behaviors worse. When intervention for self-injury is needed, it is essential to work with professionals who specialize in challenging behaviors for guidance and support. Intense, high-frequency self-injury may require protective equipment, medication management, and multiple people working directly with the individual with Down syndrome. Any self-injury that causes, or has previously caused, tissue damage, broken skin, or serious injuries should not be addressed without significant support and planning. If you are in need of support from a professional and do not know where to look, NDSS or your local affiliate group might be able to help make a connection. In situations where more restrictive interventions are indicated (emergency medications, protective equipment for the person with Down syndrome), state and local rules may dictate how those supports are provided, funded, or monitored.

You can still work to understand (through observation and data collection) to determine the function and pattern of the behavior, and plan interventions, particularly for very mild or low-frequency self-injury. For example, if the person with Down syndrome develops a new behavior where they push their hand into their chin, data collection may help us learn that this behavior is related to tooth pain. Interventions like over-the-counter pain medications may help to lessen the behavior, and treating the tooth pain may result in no more self-injury.

Like any behavior, self-injury can have any of the functions discussed above. In the example above, the function of self-injury is medical (pain relief). Self-injury can also be a particularly effective behavior with an attention function as caregivers will respond quickly to keep the person safe, but this may serve to reinforce the behavior. In another situation, self-injury may serve as an escape function if the person is removed from a demanding or difficult situation because of the behavior. These examples show the importance of considering communication alternatives as interventions so the person can meet the same need without having to resort to self-injury.

For *aggressive* behaviors:

Aggressive behavior that is high-intensity, high-frequency and/or causes injury is best understood and treated by trained professionals. Treatment of aggressive behavior may also require use of medications, protective equipment for those supporting the person, and highly structured and consistent intervention. In situations where more restrictive interventions are indicated (emergency medications, protective equipment), state and local rules may dictate how those supports are provided, funded, or monitored.

The term 'aggression' is used here as a catch-all for any number of specific presentations (hitting, kicking, slapping, pushing, pinching, biting, head-butting, throwing items, etc.). For this reason, it is important in your initial data collection that you clearly define what aggression looks like for the specific person you are working with. As stated above, remember that the same behavior may serve distinct functions in different environments or with different caregivers, so careful definition and data collection in different settings can be important.

Aggressive behavior toward others may be the person's attempt to modify their environment, such as when one person makes loud noises, and the person with Down syndrome aggresses toward that person to get them to stop. This behavior could serve as an escape function if the result is that the noises stop. Providing the person with a break, offering noise-cancelling headphones, or addressing the noise with the other person can all be more effective ways for the person with Down

syndrome to escape the loud environment. Aggression can also be an effective way for a person to access tangible items, particularly when the person is given a preferred item to make them stop aggressing. Although these interventions are done with the best intentions, they may inadvertently reinforce the behavior.

For *elopement* behavior (running away, leaving supervision, etc.):

Elopement behavior can be minor (running out of the room) but can range in severity (running into traffic, going missing). More significant elopement may require the involvement of first responders, crisis intervention services, and other agencies. Some interventions for serious elopement may be considered rights restrictions or aversive interventions (automatic door locks preventing egress, use of cameras to monitor the person, use of GPS or other tracking devices) and may require additional levels of approval and oversight. For these reasons, significant elopement should involve trained professionals in working with elopement.

Regardless of the nature of the person's elopement, data collection and intervention should follow the same steps we have described. Elopement often serves as an escape function for the person, but other functions should be considered, as well. In situations where the person elopes and is chased or followed, this may be an attention function. If the person consistently elopes to go to a preferred place or to find a preferred item, it may be a tangible function. Like we have noted with other behaviors, this highlights the importance of careful definition and data collection of elopement.

There are many technology-based supports marketed to people with disabilities and their families. Many of these solutions are helpful and thoughtfully designed but need to be considered for the specific person you are working with. For example, a GPS tracking watch may seem like a great option, but if the person does not like the feeling of the watch on their arm, it may not help. AirTags, or other tags with GPS locators, can b that have GPS locators can be another option, but it can be difficult to get the person to leave the device alone if it is in a pocket. In some cases, these can be sewn into clothing or shoes, but what happens if the person elopes without their shoes? Technology solutions are very promising but need to be carefully considered

for each individual person. As noted earlier, some of these tools may be considered rights restrictions or aversive interventions depending on age, guardianship status, and location, so it is important to work with local professionals who understand the relevant regulations.

Another important consideration with elopement is if the individual is drawn to water. Unfortunately, there are frequent news stories of people with disabilities who go missing and are found deceased or injured in or near bodies of water. For this reason, swimming lessons and/or water safety training are highly recommended, particularly if they are drawn to water and have elopement behaviors.

Conclusion

Understanding and intervening with challenging behavior in people with Down syndrome can be difficult, time-consuming, and frustrating at times. Given the demanding nature of this process, it is important to start early to learn why the behavior is occurring and to design interventions to reduce or eliminate the behavior. The steps described above can be a guide to this process. Anyone working with an individual with Down syndrome should be sure to involve the individual's entire team in these efforts. This may include family members, school staff, employment or day program staff, social service agencies, and other professionals trained in understanding behavior. When a team is communicating well, working consistently, and focused on a specific goal, the individual can learn new, more efficient ways of meeting their needs. This can help the person reach their goals and improve their quality of life.

Name of person having the behavior:

Location of data collection:

Name of witness:

Target behavior:

Person completing this form:

Data Collection Sheet

Date Time	A - What happened before? List anything you can; even if it doesn't seem to pertain to the behavior	B - What the person do? Briefly describe the person's behavior	C - What did you do? (e.g.; ignored, asked to stop, gave something, verbally redirected to a specific task, etc...)

Navigating Behavior

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