

Challenging Behavior in Down Syndrome: Initial Surveys Evaluating Co-occurrence

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ABSTRACT

Down syndrome (DS) is a developmental disability caused by trisomy of chromosome 21 and as with other developmental disabilities, individuals with DS may present with challenging behavior (e.g., aggression, tantrums, self-injurious behavior; Feeley & Jones, 2006). The purpose of this study was to evaluate the presence of challenging behavior in those with DS by surveying caregivers of individuals with DS via Qualtrics. A link to our survey was sent out to national and local organizations that support the DS population with a request to disseminate the link. Given limited response, the survey was modified (shorted and reorganized) and a link to the revised survey was disseminated via Facebook to groups focused on DS. Although both surveys received limited responses, there are preliminary findings worth exploring further. Aggression, noncompliance, and tantrum behaviors were frequently reported behavior and, escape and attention were the most reported perceived functions of behavior. Challenging behavior is reported in DS by caregivers. Future research should be conducted to examine the prevalence and function of challenging behavior in DS to develop effective preventative approaches to challenging behavior while promoting skill acquisition.

Introduction

The estimated number of individuals born with Down syndrome (DS), a disorder caused by full or partial trisomy of chromosome 21 (Kazemi et al., 2016), worldwide each year is 3,000 to 5,000 (Presson et al., 2013). There are many shared characteristics of those with DS which include comorbid health conditions and associated stereotypes, such as always being happy and passionate (Gilmore et al., 2010). A diagnosis of DS may be accompanied by physical, psychological, and functional conditions (Lukowski et al., 2019). For example, a survey of existing health conditions in young adults with DS found that many experienced eye and vision problems, hearing deficits, cardiac conditions, and respiratory issues (Pikora et al., 2014).

Additionally, many individuals with DS experience psychological disorders such as mood disorders, anxiety, and dementia (Capone et al., 2006; Nevill & Benson, 2018). Regarding the behavioral phenotype of DS, the presence of challenging behavior has been noted (Feeley & Jones, 2006). Challenging behavior is defined as a pattern of behavior that adversely impacts learning and social interactions with others (Smith & Fox, 2003). Early work has found that children with DS were more likely to engage in challenging behavior such as noncompliance and social withdrawal than children who did not have DS (Coe et al., 1999). More recent work has found that students with DS engage in multiple topographies of challenging behavior with varying frequency and degrees of severity (Saloviita et al., 2016).

Although research has determined that challenging behavior is not uncommon amongst those with DS, the factors that contribute to, or evoke, challenging behavior are not well-understood within this population. Preliminary work has identified that negative life events and stressors are positively correlated with irritability and hyperactivity in adults with DS as reported by caregivers (Nevill & Benson, 2018). However, the extent to which those with DS are impacted by psychological and behavioral disorders varies within the literature with some studies reporting a higher

prevalence of specific psychological disorders (psychosis in adolescent and young adults with DS; Dykens et al., 2015) and other reporting discrepancies based on the presence of an intellectual disability (cf., Charlot et al., 2021). Work examining the use of psychotropic medication to address mental health concerns of those with DS has found that the use of psychotropic medication is common (Kerins et al., 2007), increases with age, and the type of medication prescribed also varies with age (e.g., Downes et al., 2015).

Challenging behavior has been shown to be associated with the presence of psychological disorders (Myrbakk & von Tetzchner, 2008), limited communication skills (Smith et al., 2020), physiological conditions (e.g., illness or injury; deWinter et al., 2011) and with greater use of psychotropic medication (Bowring et al., 2017). Given all this, it is important to understand the prevalence of challenging behavior in DS and the factors that contribute to engagement in challenging behavior to promote skill acquisition and high quality of life for those with DS. Therefore, purpose of this survey was to identify the prevalence of challenging behavior in DS and any characteristics that might contribute to challenging behavior. This work entailed two surveys. Survey one was created and disseminated prior to the start of the COVID pandemic and received a limited number of responses, so the survey was modified, and a different method of dissemination was used for survey two.

Survey One

Methods

Participants

The intended participants of this study were caregivers of individuals with DS. For Survey One, 17 individuals began the survey; however, 14 provided some responses, and only 5 completed the entire survey. The survey remained open for three months.

Dissemination

In total, there were eight national and local (city, state) DS organizations contacted with an email that explained the goals of the research, the types of questions in the survey, length of time to complete the survey, and language to be shared with potential respondents. We also provided contact information for the research team and made a request for the organization to disseminate the survey via the link provided. Only one organization responded in the affirmative (the number of individuals who received the invitation to complete the survey is unknown).

Survey Description

Based on an earlier literature review of challenging behavior in DS (authors, under review), a survey was created using Qualtrics. The beginning of the survey requested demographic information of the caregiver (i.e., age range, gender, race/ethnicity, language spoken in the home, how long they have been caring for the individual with DS, highest level of education, and marital status). The next section requested demographic information of the individual with DS (i.e., age, race/ethnicity, sex, number of siblings, classroom/mode of education received, school attendance prior to the Coronavirus [COVID] pandemic, and highest grade level completed).

The next section of the survey asked questions about potential health concerns the individual with DS might have experienced followed by open-ended questions regarding the description of the condition and perceived impact on behavior. Conditions included in the survey were: visual impairments, hearing impairments and ear infection history, gastrointestinal issues, skin issues, sleeping habits and quality of sleep, cardiovascular conditions, hypothyroidism, epilepsy, mobility issues, fine motor skill issues, intellectual disability, mental disorders (type, age of onset, treatment), sensory issues, and mode of communication.

The final section of the survey focused on challenging behavior. The targeted responses were aggression, tantrum behavior, self-injurious behavior, noncompliance, disruptive behavior, and elopement. Topographies for each

targeted response were provided. Aggression included the following topographies: hitting, kicking, spitting, swatting, pushing, and throwing items at people. Tantrum behavior responses included: screaming, yelling, whining, and tantrums. Self-injurious behavior (SIB) included: head hitting, body hitting, using objects to harm oneself, hair pulling, scratching self, skin picking or picking wounds, and biting self. Noncompliance behavior was identified as ignoring task, refusing to do task, not listening, not following instructions, doing the opposite of what is told, continuing to do something after being asked to stop, and breaking rules. Disruptive behavior included: making loud distracting noises or sounds, closing eyes and laying head down on table, throwing materials, talking over people, slamming on walls, and property destruction. Elopement included running away and leaving.

Respondents were also prompted to describe any other forms of the challenging behavior not listed. There were also a series of follow-up questions for each class of challenging behavior respondents identified as an issue. These questions included the location where behavior occurred most often with the following choices provided: home, school, daycare, other (specify where); age of onset; frequency of behavior (multiple times a day, once a day, once a week, a few times a month, rarely); treatment for behavior (yes/no, ABA therapy, medication name/dose, speech, occupational therapy, other specify); how behavior had changed over time, and questions regarding the perceived function of behavior. The function of the behavior was assessed by asking respondents if they thought behavior happened to get attention, avoid something the individual with DS did not like, to gain access to an item, or for one's own pleasure (yes/no/not sure).

Results

Demographics

Given the low responses, we are reporting results of all data collected. Regarding gender of respondents, a majority were female (13 out of 14 responses), and their age ranges were between 18 years to 60 years of age. The most common reported race was White (11 out of 13 responses). The remaining caregivers identified as Hispanic/Latino/Spanish origin (N=1) and Black/African American (N=1). Mean length of time caring for an individual with DS was 15.15 years (range, 5 to 35 years; 12 responses). Of those who provided responses on caregiver education, four had a bachelor's degree, three had a master's degree, two had some college, one had an associate degree, and one had attended trade or craft school. Responses were provided for 12 individuals with DS. Their mean age was 20.82 years (range, 5 to 67 years) and five were male and seven were female. Of the individuals with DS, 10 were reported to be White, one was reported to be Multiracial/Multiethnic, and one was reported to be Hispanic/Latino/Spanish origin. The number of siblings reported for individuals with DS ranged from one to "more than 4" (11 responses). Prior to COVID-19, many individuals attended school (8 of 12 responses), with most being in a combination of both a self-contained and full-inclusion classrooms (4 of 8 responses), followed by full-inclusion classroom (3 responses), and one report of a self-contained classroom. The highest grade completed by the individuals with DS ranged from pre-school to some college (12 responses), with most individuals completing second grade and 12th grade (2 responses respectively).

Health Conditions

Visual impairment was common (7 of 12 responses), and three respondents indicated that eyeglasses were used; however, respondents stated that this visual impairment did not affect behavior (6 respondents). One caregiver commented that the individual with DS became "agitated if he does not have [glasses] on." Regarding hearing impairments, six (of 11) respondents reported hearing impairments (i.e., hearing loss and fluid buildup). The age of onset for these hearing impairments ranged from one to 50 years of age. Two respondents indicated that this impairment affected behavior. One respondent noted that the individual with DS "becomes agitated if he cannot hear you/when he mishears

you and thinks you have said something other than what you said.” One individual was reported to wear hearing aids. Additionally, five of the respondents reported frequent ear infections, however, these infections were not perceived to influence behavior.

Gastrointestinal issues were present in seven of the 11 surveys completed and included constipation (N=4), gastroesophageal reflux (N=2), duodenal atresia (N=1), and inflammatory bowel disease (N=1). These gastrointestinal issues were reported to affect behavior by increasing irritability (N=4). There were four (of 10) surveys indicating issues with sleep which were associated with a lack of concentration (N=1), confusion (N=1), and agitation (N=2). Respondents also indicated that individuals with DS experienced hypersensitivities (N=6) to sound (N=6), touch (N=3), light (N=2), taste (N=2), and smell (N=1) with many experiencing multiple sensitivities and which were reported to be associated with disruptive behavior (N=6). One respondent reported, “...exhibits deregulation, in classroom, has severe melt downs...” Other common health concerns reported included skin conditions (N=7), hypothyroidism (N=5), cardiovascular issues (N=4), and seizure disorder (N=1). None of these conditions, when treated, were perceived to affect behavior.

Five respondents (out of 10) indicated issues with mobility citing “poor balance,” “painful joints,” and “difficulties standing or walking.” Frustration and agitation were identified as related concerns, particularly when having to walk long distances. Two respondents indicated challenges with fine motor skills. Of this sample, nine (of 10) respondents indicated the presence of an intellectual disability with a broad range of abilities reported (e.g., first-grade reading level to four semesters of college). Responses regarding mental disorders indicated the presence of anxiety disorder (3 of 6 responses), attention deficit/hyperactivity disorder (ADHD; 2 of 6 responses), and autism spectrum disorder (ASD; 2 of 6 responses). Most individuals were not receiving medication for these conditions (6 of 9 responses). Finally, seven respondents indicated vocal speech as the mode of communication, one used a device to communicate, and one had limited communication. Four respondents reported that challenges with communication were often associated with frustration.

Challenging Behavior

Aggression. A total of eight respondents indicated the presence of this class of behavior. The most common of aggressive behavior reported were hitting (N=5) and throwing items (N=5). Other aggressive behavior reported were kicking (N=4), swatting (N=3), spitting (N=1), biting (N=1), and head butting (N=1; three additional respondents indicated other behavior but did not specify). Aggression was reported to occur most frequently at home (N=4) with additional locations such as school (N=2) and in public (N=1). The age of onset of aggression ranged from two to 60 years (seven respondents). Treatments for aggression included medication (N=3), speech therapy (N=1), occupational therapy (N=1), and “other” (N=2). The frequency of behavior and perceived function varied (Table 1). The function of behavior was perceived to be to gain attention, to avoid something/escape, or to gain access to something. With respect to change over time, three respondents indicated that aggressive behavior had decreased when treatment was implemented.

Tantrum Behavior. A total of seven respondents noted this class of behavior. Topographies of tantrum behavior identified were crying (N=7), yelling (N=6), and screaming (N=5). Tantrum behavior was reported to occur in multiple locations and at home (3 of 7 responses respectively). Furthermore, the age of onset ranged between two and 67 years with half of the individuals having received treatment (3 of 6 responses which included medication, speech therapy, occupational therapy, and behavioral intervention). Although the most common perceived function of tantrum behavior was escape, additional functions of the behavior were also indicated (Table 1).

Self-injurious Behavior. Multiple topographies for SIB were reported with skin picking reported by two respondents and other forms of self-injurious behavior reported by three respondents (a total of five respondents reported this class of behavior). Other reported topographies of SIB included head-butting (N=1), body-hitting (N=1), using objects to harm oneself (N=1), hair-pulling (N=1), and scratching oneself (N=1). The age of onset ranged between two and 67 years of age and these behaviors were largely untreated (3 of 4 responses; reported treatment was

lotion for skin irritation). Two respondents indicated that SIB was less likely to occur as the individual aged. The most common perceived function was escape (Table 1).

Noncompliance Behavior. A total of seven respondents indicated the presence of this class of behavior. The most common reported topography of noncompliance was not following instructions and not listening to the caregiver (N=6), followed by refusing to do the task (N=5), ignoring the task (N=5), doing the opposite of what was told (N=3), and continuing to do a task after being asked to stop (N=2). The age range for these behaviors was two years to 67 years and were reported to occur most often multiple times a day (3 of 7 responses; Table 1) in multiple locations (N=3), at home (N=3), and at school (N=1). Most respondents indicated that individuals were not receiving treatment (5 of 7 responses; treatment reported included a combination of medication and speech or behavioral intervention). Two respondents indicated that behavior had reduced whereas others did not report significant changes.

Disruptive Behavior. A total of five respondents reported this class of behavior. The most common topography reported was closing eyes and laying heads on the table (3 of 5 responses), then throwing materials (N=2), talking over others (N=2), slamming walls (N=1), and property destruction (N=1). The age of onset for disruptive behavior ranged from two to 15 years of age and occurred at home (N=3) and school (N=2). This class of behavior varied in frequency and function (although most common was escape; Table 1). Most respondents indicated treatment was not delivered (4 of 5 responses); however, the one respondent who reported treatment, the treatment included medication and the use of “consequences” which reportedly resulted in a reduction of disruptive behavior.

Elopement. A total of five respondents reported this class of behavior. Running away was the most common elopement response (4 of 5 responses). These behaviors most often occurred at home (N=3) and the age of onset ranged from two years to 11 years old. Most did not receive treatment for elopement (3 of 5 responses; reported treatment was medication and behavioral intervention or “other”). As with other topographies, the frequency and perceived function of elopement varied (see Table 1).

COVID Pandemic

Those respondents who completed questions regarding the effect of the COVID pandemic communicated that the individual with DS was negatively affected by difficulty wearing masks, increased confusion and nervousness, and an inability to keep up with a normal routine. One respondent stated that the COVID pandemic had “made it very difficult” for the individual with DS.

Survey Two

Methods

Participants

The participants in this study included caretakers and parents of individuals with DS who completed the survey. In total, there were 31 surveys started. Of the 31 surveys initiated, 23 surveys had limited responses/were incomplete, and 16 were completed fully. The survey remained open for three months.

Dissemination

This set of respondents was potentially reached through posts made in DS-specific Facebook groups based in the United States, Mexico, and Pakistan. The groups were discovered through a search on Facebook as well as a google search for DS organizations. The administrators of each Facebook group were sent a message that explained the goals of the research, the types of questions in the survey, and the length of time to complete the survey. We also provided contact information for the research team and made a request for the organization to disseminate the survey via the link provided. Groups from Facebook were emailed if they failed to respond to a Facebook message, if they

requested an email from the research team, or if it was a Gigi's Playhouse organization. Much like the first survey, the email explained the goals of the research, the types of questions in the survey, length of time to complete the survey, and language to be shared with potential respondents. We also provided contact information for the research team and made a request for the organization to disseminate the survey via the link provided. In total, 119 organizations were contacted and seven agreed to disseminate the survey on our behalf. The date of contact with an organization was recorded and those that did not respond to the email were sent a final reminder three months after first being contacted.

Survey Description

We altered this Qualtrics survey by rearranging the sections so that those items regarding challenging behavior followed participant demographics. Questions regarding COVID were also omitted. We also shortened and simplified responses by adding drop-down boxes when an affirmative response was provided and forwarding to the next set of questions if a negative response was provided. The content of this survey was similar to survey one.

Results

Demographics

Given the low responses, we are reporting results of all data collected. The respondents were overwhelmingly female (22; with one male respondent). The age range of the respondents was between 30 years and over 60 years of age. Most of the respondents were also White (N=17) with others reporting to be Black/African American (N=2), Asian (N=2), and of Hispanic/Latino/Spanish origin (N=1). Regarding caregiver education, six had a bachelor's degree, three had a master's degree, five had some college, two had an associate degree, and three had a professional degree beyond bachelor's degree. The mean length of time spent caring for an individual with DS was 10.2 years (range, 2 months to 32 years). Of the individuals with DS, six were males and 16 were females. Of the individuals with DS, 15 were reported to be White, two were Black/African American, two were reported to be Multiracial/Multiethnic, one was reported to be of Hispanic/Latino/Spanish origin, and one Asian. The number of siblings reported for individuals with DS ranged from one to "more than 4" (20 responses). In terms of schooling for the individual, one respondent indicated that the individual with DS has completed school above 12th grade but did not specify how many additional years of education obtained; whereas one respondent indicated no completion of school. Most individuals were reported to have been in kindergarten to fourth grade (N=10) and one respondent indicated the individual was in school but did not indicate which grade.

Challenging Behavior

Aggression. Of the 23 surveys initiated, a total 14 respondents reported this class of behavior. The most common behavior was hitting (N=11) followed by pushing (N=10), throwing items at people (N=9), and kicking (N=8). Most caregivers reported that the primary location of aggressive behavior was at home (N=7) and others reported that this behavior occurred in multiple locations (N=4). The age of onset of aggression ranged from two to sixteen years of age with three respondents indicating behavior began at approximately two years of age. Three caregivers reported medication was used to treat this class of behavior. Other reported treatments for aggression included occupational therapy (N=3), speech therapy (N=3), and behavioral therapy (N=1). The frequency of behavior and perceived function varied (see Table 2). The function of behavior was most often perceived to be to avoid something/escape; however, all potential functions were indicated. With respect to how this class of behavior progressed, some reported that the behavior had gotten better with age (N=6) or behavior had gotten worse (N=2).

Tantrum Behavior. A total of eight respondents reported this class of behavior. The most common behavior was crying (N=7) followed by yelling (N=5), whining (N=4), tantrum (N=4), and screaming (N=3). Tantrum behavior was also reported, by five respondents, to occur in various locations (i.e., home, school, public places, doctor offices, stores, relative's homes). The reported age of onset for tantrum behavior was two to seven years of age. The reported frequency of behavior and perceived function varied although all reported the occurrence to be common and the functions to be primarily socially mediated (see Table 2). Regarding the change of tantrum behavior over time, most indicated that tantrums had escalated over time (N=6) while two indicated that behavior had improved. Three respondents indicated treatment had been initiated for this class of behavior which included medication (N=1), behavioral intervention (N=1), speech therapy (N=2), and occupational therapy (N=2).

Self-Injurious Behavior. A total of five respondents reported this class of behavior with the most common topography being head hitting (N=5). Other reported topographies included biting self (N=3), scratching self/skin picking (N=2), and body slamming (N=2). Respondents indicated that SIB most often occurred at home or place of residence (N=4). The reported age of onset ranged from two to nine years of age. The frequency of occurrence and perceived function of SIB varied; however, respondents did not perceive SIB to have an attention-seeking function (Table 2). Two respondents indicated that SIB had decreased over time and two reported that behavior had increased over time. Only one respondent noted treatment for SIB which was indicated to be "other."

Noncompliance Behavior. There were 15 respondents who reported the occurrence of noncompliance behavior, specifically, the individual continuing to do things when asked to stop. Also reported were ignoring tasks (N=14), refusing to do task (N=13), does not listen (N=13), does not follow instructions (N=12), doing opposite of what is told (N=8), and breaking rules (N=5). The primary location of behavior was home (N=9), school (N=5), public places (N=2), and friends/family homes (N=1) and often the behavior occurred in across multiple locations (N=7). The age of onset for this class of behavior ranged from birth to 16 years of age. The frequency of occurrence and perceived function of noncompliance behavior varied; with most respondents perceiving an escape function for the disruptive behavior (Table 2). There were seven respondents who indicated treatment for noncompliance which included medication (N=2), speech therapy (N=2), occupational therapy (N=2), applied behavior analysis (N=1), and "other" not specified (N=4). Regarding changes over time, four respondents indicated that behavior had improved over time.

Disruptive Behavior. A total of nine respondents reported this class of behavior which included throwing materials (N=8), making loud distracting noises (N=5), closing eyes and laying head down (N=4), slamming on walls (N=3), talking over people (N=3), and property destruction (N=2). Most individuals reported that this class of behavior occurred in multiple settings, specifically home (N=9) and school (N=4), with five respondents indicating home as the primary location. The age of onset for disruptive behavior ranged from two to 16 years of age. The frequency and perceived function of disruptive behavior varied; with most respondents perceiving an escape function for the disruptive behavior (Table 2). Four respondents reported that disruptive behavior had been treated with occupational therapy (N=1), medication and behavioral intervention (N=1) and "other" (N=2). Regarding how behavior had changed over time two, respondents reported behavior had decreased and five reported that behavior had not changed drastically.

Elopement. A total of ten respondents indicated elopement as a behavior of concern. Most individuals were reported to elope from home (N=6), school (N=4), public places (N=4), and friends/family homes (N=1). The most common reported age at which this behavior began was two to four years of age (N=8). The frequency and perceived function of elopement varied, with most respondents perceiving a function of self-pleasure and escape (Table 2). Three respondents reported treatment for elopement which consisted of medication (N=2) and environmental arrangement (N=3). Five respondents indicated that elopement has decreased or become manageable.

Health Conditions

Visual impairment was indicated in nine of the 16 responses and all those individuals were reported to use eyeglasses. All respondents indicated that this impairment did not affect behavior. Regarding hearing impairment, five of the 16

respondents indicated mild to moderate hearing loss (only two individuals reported using hearing aids). These impairments were detected between the ages of birth to 12 years of age. When asked about frequent ear infections, four respondents indicated recurring ear infections and three of the four respondents indicated that challenging behavior was often associated with the presence of an ear infection, “Unusual bad behavior was usually the first sign of an ear infection. He was not feeling well, but could not verbally express it, so he would act out, hit, cry, etc.”

Six respondents also indicated the presence of gastrointestinal issues, specifically, constipation (N=3), loose bowels (N=1), inflammatory bowel disease (N=1), and gastroesophageal reflux (N=1). Of this group, four respondents indicated the presence of symptoms associated with these conditions affect behavior often increasing the likelihood of challenging behavior. Seven (of 16) respondents reported sleep disturbances, specifically sleep apnea (N=3) and difficulty falling or staying asleep (N=4). Primary observations of impact on behavior related to tiredness. Sensory hypersensitivity was also reported (N=9) which included sensitivity to sound (N=8), touch (N=4), taste (N=4), sight (N=3), and smell (N=2) with several experiencing multiple sensitivities (N=5) and which was perceived to impact behavior (N=9). One respondent noted, “If it's too loud she will freeze up or scream.” Other common health concerns reported were skin problems (N=9), hypothyroidism (N=6), cardiovascular issues (N=7), and seizure disorder (N=1). As with the previous survey results, these conditions, when treated, did not appear to affect behavior.

Five respondents (out of 16) reported the presence of problems with mobility which were primarily difficulty standing and balance problems. One respondent reported dropping to the ground while going on walks. Nine respondents (out of 16) reported issues with fine motor skills which impacted ability to write and eat. Four respondents indicated that there was frustration with tasks that involved fine motor skills. Of this sample, 12 (of 15) respondents indicated the diagnosis of an intellectual disability with varying ranges of ability. Additionally, only one respondent indicated a diagnosis of a mental disorder (anxiety, depression, intermittent explosive disorder, and ASD) and medication was prescribed to treat this disorder. Finally, with regards to communication, a majority of the sample communicated vocally (N=13) with others using a combination of communication strategies. As with the first survey, frustration was noted to be a common occurrence when others had difficulty understanding communication.

Discussion

The purpose of these surveys was to ascertain how prevalent challenging behavior was for individuals with DS and to explore if there were any characteristics that might contribute to challenging behavior. Admittedly, these surveys had very low response rates and thus it is difficult to draw any generalizable conclusions regarding challenging behavior in DS. However, these findings do provide potential avenues for further inquiry. It is clear that challenging behavior does occur in the DS population. In both surveys, noncompliance behavior, disruptive behavior, aggression, and elopement were reported behaviors of concern (SIB, although reported, did not seem to occur very often and there were differences observed between survey one and two regarding the occurrence of tantrums).

How these behaviors change over time and what factors contribute to their occurrence should be further investigated. For example, respondents indicated that when interventions (i.e., medication and other therapies) were used aggression decreased over time. However, the factors that contributed to the presence of aggression are not well understood. Throughout the survey, questions regarding health conditions and communication skills suggested that frustration associated with these conditions (e.g., gastrointestinal disorders, hypersensitivity, sleep disruption, mobility/fine motor issues, and limited communication skills) could potentially be associated with aggressive or other challenging behavior. Although there did not appear to be a particular pattern with regard to the location where challenging behavior occurred, it is possible that stimuli within these environments (i.e., home, school, public places) were more likely to contribute to their occurrence.

When we examined the perceived functions of challenging behavior as reported by caregivers, it appears that the frequency of behavior varied with few discernable patterns. For example, survey one revealed that frequency of all challenging behavior varied, so topography did not seem to coincide with regularity of presentation; whereas for survey two, many of the classes of challenging behavior appeared to occur with great regularity. When looking at

function of behavior, both surveys revealed that escape was a common perceived function for all classes of challenging behavior whereas attention was not a perceived function of SIB. Understanding the situations in which individuals with DS may be attempting to escape and why (e.g., a skill deficit that can be addressed, aversive elements of a task that can be modified) is important for addressing behavior that might pose barriers to accessing education and community.

In both surveys and for many of the challenging behavior classes surveyed, caregivers reported that medication was an intervention used to address behavior. Medication use within the DS population should be examined. Recently, concerns have been raised about the potential overuse of psychotropic medication to address challenging behavior in individuals with intellectual and developmental disabilities (Royal College of Psychiatrists, 2021). Learning more about the conditions under which these behaviors are likely to occur can ensure that when psychotropic medications are prescribed as a part of the treatment package they are warranted and used efficaciously.

Admittedly, a significant limitation of this study was the low number of surveys fully completed. However, these data do provide a basis from which to begin to further explore the potential factors that may contribute to the presence of challenging behavior in the DS population. We hope that this work prompts further investigation into the occurrence of challenging behavior and the treatment and prevention of challenging behavior in DS.

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Table 1
Reported Frequency and Function of Challenging Behavior from Survey One

Frequency	Aggression (N=8)	Tantrum Behav- ior (N=7)	SIB (N=5)	Noncompliance Be- havior (N=7)	Disruptive Behavior (N=5)	Elopement (N=5)
Rarely	1	2	0	1	0	2
Few Times a Month	1	1	1	1	2	2
Once a week	1	2	0	0	0	0
Once a day	0	0	1	2	2	1
Multiple Times a day	3	2	1	3	1	0
Function						
Attention	1	1	0	2	2	0
Escape	3	3	2	5	3	2
Tangible	3	2	1	2	2	1
Self-Pleasure	1	1	1	2	1	2

Note. Not all respondents provided answers regarding the frequency or perceived function of challenging behavior; thus, the numbers do not total N.

Table 2
Reported Frequency and Function of Challenging Behavior from Survey Two

	Aggression (N=14)	Tantrum Behav- ior (N=8)	SIB (N=5)	Noncompliance Be- havior (N=15)	Disruptive Behavior (N=9)	Elopement (N=10)
Frequency						
Rarely	1	0	1	2	1	2
Few Times a Month	1	1	1	2	2	0
Once a week	3	0	1	1	1	1
Once a day	3	4	0	2	2	2
Multiple Times a day	5	2	1	8	3	3
Function						
Attention	5	4	0	6	4	3
Escape	7	5	2	13	7	6
Tangible	6	5	3	7	4	5
Self-Pleasure	2	1	1	3	3	6

Note. Not all respondents provided answers regarding the frequency or perceived function of challenging behavior; thus, the numbers do not total N.