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Strategies to Address Challenging Behaviors in Children with Down Syndrome

Emily Sproat

Illinois State University, sproate14@gmail.com

Ciera M. Lorio

Illinois State University

Kimberly Adelman MS CCC-SLP

Illinois State University

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STRATEGIES TO ADDRESS CHALLENGING BEHAVIORS IN CHILDREN WITH DOWN
SYNDROME

EMILY SPROAT

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Strategies to Address Challenging Behaviors in Children with Down Syndrome

Introduction

Down syndrome (DS) is a genetic disorder results from an extra copy of the 21st chromosome and is considered to be one of the most common genetic disorders (Fidler, Hepburn & Rogers, 2006). The added chromosomal material can affect the trajectory of development in many aspects of an individual's life. One aspect that could be affected includes behavior. As a future speech-language pathologist, it is imperative to develop knowledge and skills regarding how to provide therapy while managing challenging behaviors. Challenging behaviors could have long and short-term effects on the individual themselves and multiple entities in the child's environment including caregivers, teachers, peers and other professionals. The presence of challenging behaviors can significantly impact learning as well as impede social interaction with peers. The purpose of this literature review is to inform speech-language pathologists about behavioral aspects of individuals with Down syndrome, with a focus on challenging behavior, and the best application of strategies and interventions for success. There are many factors that contribute to challenging behaviors in children with DS. These may include such as sleep disturbances, phenotypes and attention deficit hyperactive disorder (ADHD). In this review, challenging behaviors will be defined, and strategies and interventions will be outlined to decrease challenging behaviors will be discussed. Finally, potential recommendations will be considered that speech-language pathologists could suggest for parents to implement at home.

Definition of Challenging Behaviors

Various challenging behaviors are common among children with DS and can occur consistently in infants with DS (Feely & Jones, 2006). Doss and Reichle (1991) describe that

challenging behavior as actions that result “in self injury or injury of others, causes damage to the physical environment, interferes with the acquisition of new skills, and/or socially isolates the learner” (p. 215) as cited by Feeley and Jones (2006). In summary, three main factors to examine when considering if a behavior is challenging include the impact regarding safety, social relationships and learning. Challenging behaviors occur for a variety of reasons, and often times it occurs as a result of difficulties communicating effectively. The reason challenging behaviors occur could be different for each individual, and there is a spectrum of challenging behaviors, mild to severe (Chandler & Dahlquist,2015). Children with and without difficulties can display challenging behaviors, and children with difficulties are at an increased risk for challenging behaviors, which includes individuals with DS (Chandler & Dahlquist,2015). These characteristics and actions could lead to breakdowns in the individual’s ability to effectively communicate with others in their environment. Feely and Jones (2006) characterized different functions of challenging behavior; they classified the behavior to obtain attention or to avoid/escape non-preferred activities. Obtaining attention could include attention from others such as parents or teachers in order to access preferred objects or activities. Additional challenging behaviors may include social and nonsocially motivated behaviors (Feely and Jones, 2006). Nonsocially motivated behaviors involve actions when children with DS pursue escaping/avoiding or obtain internal stimuli for themselves. On the other hand, socially motivated behaviors are when the child desires something from another individual in their environment.

Factors that Contribute to Challenging Behavior

Phenotype

There could be many factors that contribute to challenging behaviors for individuals with DS. One factor is potential evidence for an emerging phenotype (Feely & Jones, 2006). Researchers have stated individuals with DS experience more behavior problems than their peers (Feely & Jones, 2006). Fidler et al. (2006) describes developing evidence for an emerging DS phenotype in early childhood. A phenotype can be described as the observable characteristics individuals exhibit in the environment. Behavioral phenotypes include outcomes regarding behavioral profiles. For instance, this could include difficulties with gross motor abilities, communication, and social interaction. Behavioral phenotype can change within individuals especially when intervention is provided (Fidler et.al,2006). Fiddler et. al (2006) suggested focusing on “crucial windows of opportunity in early development to target areas that could potentially pose problems to children with DS before they become an evident area of weakness” (p.3). This illustrates how recognizing characteristics of the DS phenotype and overall development for individuals with DS could shape the intervention process. Fidler et al. (2006) discussed how individuals with DS have stronger skills regarding visuospatial processing rather than verbal processing skills. Using the strength of visuospatial process could be very helpful while providing intervention for children with DS. Focusing on an individual’s strengths could help boost confidence and motivation during intervention sessions, especially with more difficult tasks. By incorporating an individual’s strengths into therapy sessions, speech-language pathologists may prevent challenging behaviors from occurring due to frustration and lack of motivation.

Sleep Disturbances

Another factor that contributes to challenging behaviors for individuals with Down syndrome include sleep disturbances. Researchers have found that there is a potential link

between sleep and behavior within children with DS (Beebe, Byars, Esbensen, Hoffman, & Epstein, 2018). According to Beebe et al, (2018) “behavioral sleep disturbances affect 52-69% of children with Down syndrome” (p.2). For individuals with DS, sleep difficulties are often the result of multiple issues including sleep apnea (periods of not breathing and awakening), waking up during the middle of the night, as well as difficulty falling asleep.

Speech-language pathologists should be aware of how sleep can affect all children they may work with daily. Very few studies have investigated the relationship between sleep and daytime behavior. Beebe et al. (2018) study focused on school-aged children with DS and how sleep was associated with the child’s daily functioning and parental well-being. Their study included 30 children with DS. Measures were taken to achieve sleep data as well as examining daytime behavior. Parents of the children completed a sleep diary. The parents and teachers also completed measures to document behavior within the home and school settings. Data was also taken from the device the children wore that detected movement during the night. The results from these measures exhibited an increase of challenging behaviors when sleep disturbances were noted. Parents reported that sleep concerns among children have been associated with difficulties in communication, personal care, and school. Fidler et al. (2006) also discussed how further research on sleep could be beneficial regarding phenotype characteristics of individuals with DS. It is noted among typically developing children that an insufficient length of sleep, as well as sleep quality, may influence challenging behaviors exhibited at school or home. The same appears to be true for children with DS as well. Appropriate screening could potentially highlight sleep problems within children with DS, leading to appropriate interventions to help improve sleep quality and decrease challenging behaviors. Further research regarding sleep and behaviors is warranted.

ADHD

ADHD is another potential factor that could contribute to challenging behaviors. There are three main symptoms that are typically outlined for a diagnosis of ADHD. These symptoms include problems with paying attention or concentrating, acting before thinking and being very active frequently (Buckley, 2006). Typically, the diagnosis is made by a psychiatrist after diagnostic measures have been performed. There is no biomedical way of confirming a child has ADHD, such as a blood test, and it is even more difficult to accurately diagnose ADHD in a child with DS. There needs to be a consideration for overall development and speech/language delays when considering the diagnosis of ADHD in a child with DS (Buckley, 2006).

Another facet of ADHD among children with DS is overdiagnosis. Children with DS engage in noncompliant behaviors such as defying parental or teachers' directions at school or within the home setting. Therefore, children with DS are often classified with symptoms of ADHD at higher rates than similarly aged children with intellectual and developmental disabilities (Beebe et al., 2018). There is a potential for ADHD to be comorbid with DS (Laws, Taylor, Bennie, Buckley, 1999), but this does not mean there should be an assumption that ADHD is the reason for the challenging behaviors that could be occurring. As discussed, children with DS typically have stronger receptive language skills than their expressive language skills (Fidler et al., 2006). This might mean that the child knows what they would like to say but have trouble expressing their thoughts. Participating within the classroom could be more difficult, which might lead to challenging behaviors or inattention. There are many factors that contribute to an increase of challenging behaviors for individuals with DS. This is why it is

important to have intervention strategies in place that can help decrease challenging behaviors while also supporting progress in speech, language and other developmental areas.

Decreasing Challenging Behaviors

Functional Behavior Assessment

The process of a functional behavior assessment helps to determine the target behavior and why the challenging behavior is occurring (Feely & Jones,2008). The functional behavioral assessment should be administered in the environments the behavior occurs. Environmental events include setting events, antecedents and consequences. Setting events are not directly related to the immediate antecedent. The antecedent is what has occurred directly before the challenging behavior. Examples of environmental events could include, transitioning from one place to another, during lunchtime or an academic lesson in the classroom (Feely & Jones,2008). Gathering all of this information can help practitioners understand when/ how behaviors are more likely to occur, giving support personnel a better idea of what intervention would be the most beneficial for the child. After a functional behavioral assessment has been administered, a Positive Behavior Support Plan can be drafted. This support plan includes different strategies to address challenging behaviors. Once this process has been completed, practitioners can use the resulting data to guide and their plans for intervention. Conducting functional behavior assessments as well as choosing appropriate intervention strategies can lead to meaningful changes regarding challenging behavior for children with DS.

Applied Behavior Analysis

Applied Behavior Analysis (ABA) therapy is a specific intervention may be useful to address challenging behaviors displayed by individuals with developmental disabilities such as

DS (Feely & Jones,2006); however, research is lacking regarding the effectiveness of ABA used for individuals with DS. Feely and Jones (2006) define ABA as, “interventions addressing socially significant age-appropriate behaviors with immediate importance to the individuals using a precise measurement of those behaviors in need of improvement” (p.5). The principles of behavior used within ABA intervention plan include antecedent, behavior and consequences.

Feely and Jones (2008) investigated multiple behavioral strategies for children with DS. The first aspect of behavior to consider is the development of a setting event. For children with DS, setting events are especially important to consider because events such as illnesses and sleep problems at higher rates within this population (Feely and Jones,2008), (Beebe et al., 2018). For example, it was previously mentioned that children with DS have difficulty sleeping at night. If a child with DS is sleep deprived, they may be non-compliant the next day at school when the teacher asks them to complete an undesired task. The lack of sleep would be considered the setting event in this specific example. To address setting events, the foremost important step is to acknowledge that there is a relationship between the setting event and the challenging and/or non-compliant behaviors. The next step would be to record the occurrence of both the setting event and the engagement of the challenging behavior, such as a daily log of the child’s actions. This data collection will help identify a relationship between the setting event and the behavior. A relationship exists if there are more occurrences of the non-compliant behaviors during the setting event (e.g, difficulty sleeping at night) than a non-setting event (e.g., no trouble sleeping) (Feely and Jones,2008). Both the antecedent and setting event strategies are implemented to decrease the likelihood of the challenging behavior to transpire (Feely & Jones,2008). The first step to implement an antecedent based strategy would be to apply a functional behavior assessment. The individual’s performance is how effective the intervention is with the child. of

the behavioral intervention, such as ABA intervention plan, intervention is evaluated. If the behavior is decreasing, then the behavior plan is effective. One strategy commonly used in ABA interventions includes using a prespecified reinforcer. A prespecified reinforcer involves notifying the child about what they will receive after the completion of the task at hand (Feely & Jones,2008). The reinforcing items should be anything that provides to be motivating for the child. Some examples include stickers, bubbles, and crayons. Another strategy could include using a preferred activity. This is an integral aspect of the ABA intervention. This helps to keep the child focused on the preferred item while completing the desired task. It can also be a very helpful strategy for transitioning from one activity or the other. Other strategies that are significant include high probability request sequence, offer of collaboration as well as a choice (Feely & Jones,2008). High probability request sequence is when the practitioner conveys a chain of requests. To begin the chain there is a series of requests that the child is more likely to accomplish followed by reinforcements (Feely & Jones,2008). The offer of collaboration is exactly how it is described. There is a request for an activity with an added statement of joint activity or action. The most important aspect of these strategies is to implement them before the possibility of challenging behavior occurs (Feely & Jones,2008). This is one of the best ways to achieve effective results from children with DS. Varying the different strategies to assist in the prevention of challenging behaviors is key. All of the strategies discussed above are important way for practitioners as well as parents to possibly decrease the occurrence of challenging behaviors. If these strategies are implemented before challenging behavior occur, more goals could be targeted throughout interventions, instead of focusing on managing behaviors. All of this information regarding behaviors intervention highlights the significance that speech and ABA intervention plans could assist a child with DS. The implementation of behavioral

intervention plans, such as ABA, can help the child learn to communicate successfully by decreasing challenging behaviors.

Prevent-Teach-Reinforce

Prevent-teach-Reinforce (PTR) is a type of behavioral strategy that can be implemented to decrease challenging behaviors. It was developed to address the demand of an assessment-based intervention that can be carried out in a typical school setting (Dunlap, Strain Wilson, 2011). The principles for PTR were developed based on ABA intervention plan and the useful process of positive behavior support. The individual strategies of PTR need to include at least one component of the antecedent behavior, instructional strategies and arrangement of reinforcement for future events (Dunlap et al., 2011). The process of PTR is standardized and described in a published manual. Each step resolves with a self-evaluation that the school team completes before they move on to the next step. The self-evaluation helps to ensure the standardization of this behavior intervention (Dunlap, Strain Wilson, 2011). There are five main steps of the implementation of PTR. The first is to establish a team. The most important member is the individual who is going to be implementing the intervention plan. Within the first meeting the team determines what each role the individual will play in the intervention process (Dunlap, Strain Wilson, 2011). The next step is to set goals for the specific student and identifying three to five target behaviors of concern. One will be targeted for reducing the behavior and the other will be targeted for replacing the behavior. A way to measure the behaviors will be discussed (Dunlap, Strain Wilson, 2011). Finally, the assessment for PTR will be administered. After the administration of the assessment an intervention plan can be developed. The PTR manual provides the team with guidance for selecting intervention components that work within the

school setting while meeting the child's behavioral needs (Dunlap, Strain Wilson, 2011).

Evaluation occurs throughout the process to determine the effectiveness of the intervention.

There has been some research that highlights the use of behaviorally based procedures such as ABA and PTR, to mediate and evaluate challenging behaviors in individuals with developmental disabilities (Feely and Jones, 2008; Dunlap, Strain Wilson, 2011). However, there is little research regarding children specifically with DS. There is a plethora of research regarding autism spectrum disorder regarding (ASD) challenging behavior and behavioral intervention plans. There is limited research concerning behavioral characteristics that are presented with children that have DS. This seems to be a common theme, that more research is needed, specifically within the area of addressing challenging behaviors interventions and children with DS.

Functional Communication Training

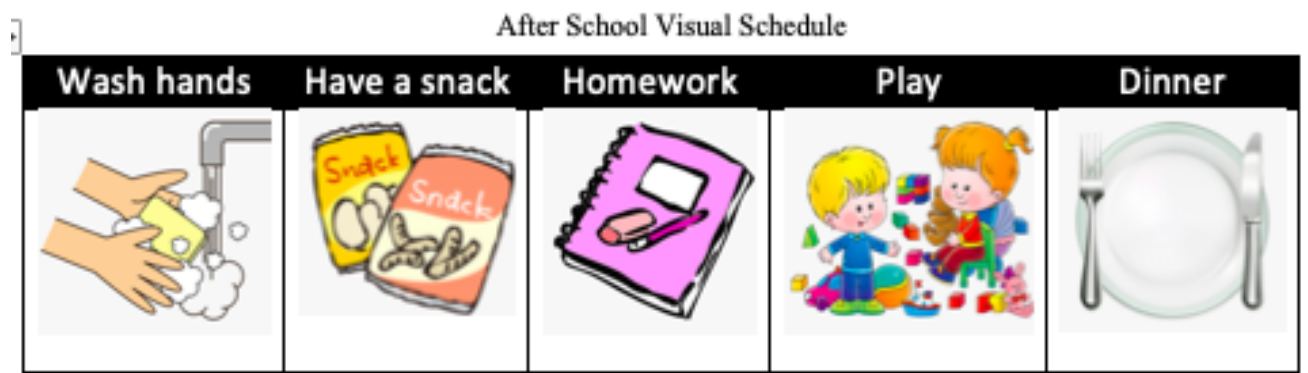
Another strategy to address challenging behavior's is called Functional Communication Training (Feely & Jones, 2006). This training entails instructing and classifying a more suitable way to communicate a response that has the same function as the undesirable challenging behavior, this could include replacing the unwanted behavior with a new skill (Feely & Jones, 2006). While using this training, it is important to reinforce the appropriate behaviors with direct contact and use tools that are motivating for the child. This aspect emphasizes how important it is to get to know the child to figure out what would be the most motivating for him or her to promote the new replaced skill. Replacement skills can then be generalized across many settings. This could lead to appropriate outcome within more context and environments for the child (Feely & Jones, 2006). Consequence strategies are another important intervention strategy for children with DS to address challenging behavior. This typically includes reinforcing

appropriate behavior as well as providing consequences for inappropriate actions. Feely & Jones (2006) found that it is important to have a mixture of consequence strategies when challenging behavior occurs.

Specific Strategies

Visual Schedules

There are also many specific strategies that could be implemented to help decrease challenging behaviors for children with DS. The use of visual schedules can also be a helpful tool that connects to expectations for the children or ties to a behavioral intervention plan. Visual schedules are relatively easy to create, and the child may even enjoy using them throughout the day. This has the potential to decrease challenging behaviors, especially if they occur during times of transitioning among activities. The visual allows the user to see exactly what is expected of them to accomplish. Children with DS are likely to achieve the highest when the activities and/or days structure is the same (Stein, 2011). A visual schedule allows for a photographic representation for a child with DS to see. Below is an example of a visual schedule self-created with clipart.



Having pictures and words on the figure permits the ideas and thoughts to be more easily accessible for children. Another added benefit could be to include a spot within the visual schedule for the children to mark when the activity has been completed. Not only are they easily accessible but they are relatively easy to create as well. School personnel could incorporate visual schedules into daily activities. Children with DS tend to respond less to verbal instructions and more to visuals (Stein, 2011).

Behavior Chart

Creating a behavior chart can help children with DS decrease challenging behaviors. It acts as another visual to see progress and shows correlations between desired vs undesired behaviors (Stein, 2011). Incorporating the child in the development of the behavioral chart could help buy into and understand the process. This could be implemented in many settings such as the speech-language pathologist's therapy room or within the classroom setting. After the chart has been made the goals should be simple and positive. This will encourage engagement from the child. Another important factor while implementing the behavioral chart is to be consistent. Consistent use of the behavior chart, as well as reinforcements from the caregivers, will assist in the child's development of skills and reduce challenging behaviors (Stein, 2011). These ideas could help promote communication, understanding and impede challenging behaviors as much as possible.

Choices

Providing choices for a child has proven to be an effective form of behavioral intervention. Giving the child different options often reduces behaviors since they have some control over their actions. This strategy often works even if choices are not the child's preferred activities. This could be performed at home or in the school setting. Within the school setting

there can be choices, although it could be more difficult for a teacher to provide choices in a classroom environment while teaching the entire class. This action would require more a bit more planning for the teacher. It could be easier to provide choices in a small group setting or one-on-one (Stein,2011). This could be effective in a therapy session when trying to accomplish tasks that are not preferred. Offering choices has been effective for children with ASD, research is developing for children with DS.

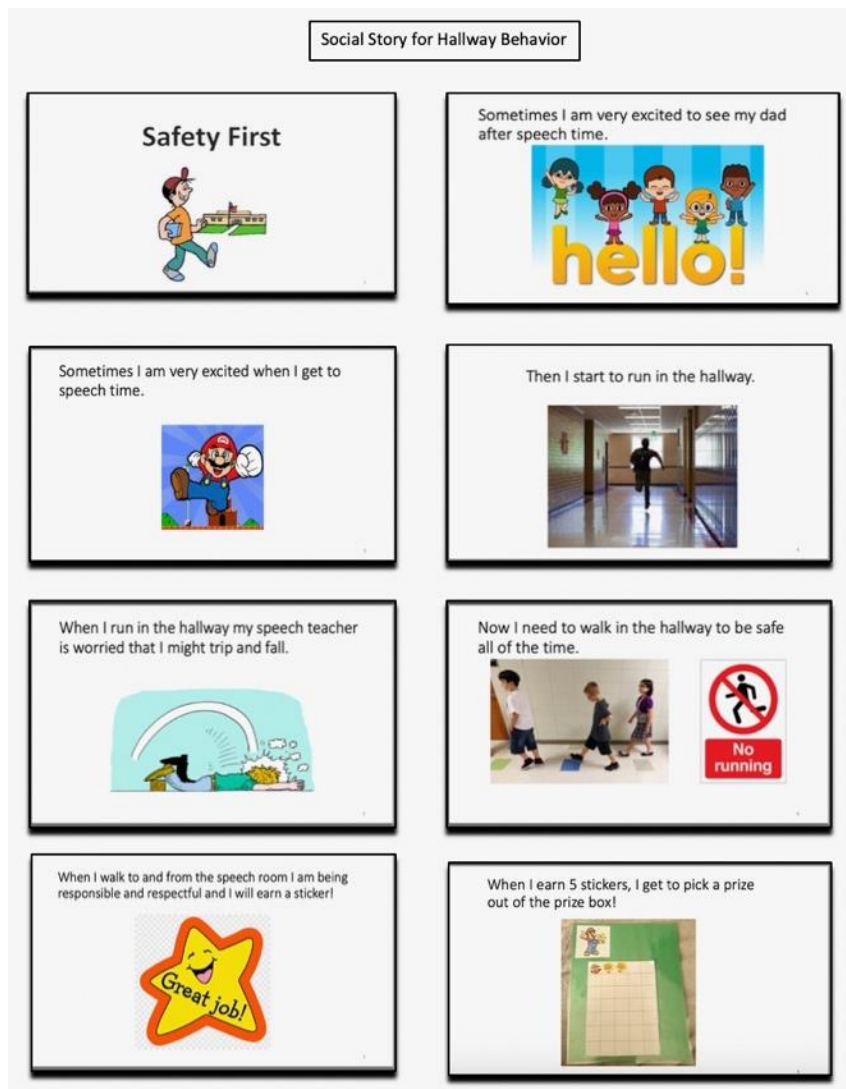
Clear and Concise Speech

Another process that could be implemented is giving clear and simple directions. As previously discussed, language can be frustrating for children with DS (Stein, 2011). Reducing language output is important while talking to the child. This is a crucial idea for parents as well as other professionals to recognize. The more complicated and elongated the language output is the more likely the child will not respond positively. While giving directions to a child, it should be straightforward. An example of a directive statement could be “Put your shoes on now, please”. A non-directive statement could be “Could you please put your shoes on before we need to leave for the park?” (Stein, 2011, pg.5). These models highlight the importance of refraining from using questions while talking to children with DS. Questions give the illusion that there is a choice. It is imperative to be directive when talking to children. Asking a question gives the child the opportunity to say “no”. This could be a time when challenging behaviors occur (Stein, 2011). Caregivers know the child the best and can anticipate when activities are becoming more difficult thus leading to an increase of challenging behaviors.

Social Stories

Social stories are great, especially for children with DS. These stories are written specifically for the student and the situation at hand. This teaching method involves

understanding of social context of various social situations (Stein,2011). This tool can help lessen the stress of social situations as well as prompt individuals to make more appropriate choices. This method outlines potential events in a child's life (Stein, 2011). Typically, this occurs through a book format and pictures. The stories usually are in first person, this way the child can think about themselves in the different aspects throughout the story. Some difficult events or behaviors that could be used for social stories include inappropriate hallway behavior, going to the doctor and the first day of a new school. The picture below is an example of a social story that was self-created for an individual with challenging behaviors in the hallway.



Recommendations for Parents

Parents might feel like they are alone on this journey with their child. There are many resources for parents such as the school system, healthcare providers as well as other community resources that could help provide support. A huge aspect that is reiterated throughout this literature review is the aspect of early intervention. The earlier the child receives services; the quicker specific skills can be targeted. Targeting skills early could reduce some challenging behaviors in the future. A pediatrician can help parents rule out medical causes of behavior problems such as sickness and poor sleep. This process could also include looking at other factors that affect the child with DS's behavior such as cognitive skills, and their social and emotional well-being (Stein, 2011). Parents could even ask for a child's behavior to be assessed by professionals within the school district. Speech-language pathologists can be a crucial member on the care team. As a professional having an open line of communication with parents is a crucial aspect of the intervention process. Many of the specific strategies discussed above such as a visual schedule or behavior charts could be implemented at home. The speech pathologist could explicitly show parents how to create a visual schedule or social story. They could also develop one and then send it home with the child. There are also many techniques that parents can use at home to help with daily actions that could have a huge impact one is establishing a routine. Neurotypical children, as well as parents, tend to perform the same actions within the same order every day. Routines can make daily activities easier and are especially important for children with DS, even at school. The aspect of knowing what is going to happen next is very important for children with DS. A speech pathologist could recommend for parents to be consistent with their child, especially when challenging behaviors occur. If there are

expectations set for the child, the challenging behaviors might decrease. Collaboration and consistency are crucial for behavior plans as well as when intervention has been implemented. Also, it is crucial for practitioners in any field to involve the caregivers in as many aspects of the child with DSs intervention. Caregivers should be included in the development and implementation of a behavioral plan. Professionals need to explain the behavior intervention techniques to caregivers so they can be implemented at home. Collaboration will also play an important role within the school or other settings; this could be involving the classroom teacher and other professionals such as occupational or physical therapists to carry over a behavior plan.

Future Research

Another interesting facet was brought up by Jacola's study (2014) about challenging behavior in adolescence. Adolescence is a time that is characterized by an increased risk for behavior problems and mood changes. The results included that adolescents with DS have a higher frequency of behavior problems than age-matched peers (Jacola et al.,2014). This begs the question, would more communication exposure with a variety of communication partners for children with DS while they are younger lead to a decrease of challenging behaviors as they age? Functional communication skills as well as providing many social interactions with a variety of communication partners is important for individuals with DS (Feely & Jones,2006; Feely & Jones,2008). More research regarding this topic could lead to quality evidence-based practice ideas, which could benefit many individuals within the DS community.

Conclusion

As a future speech language pathologist, it is imperative to develop the knowledge and skills regarding how to provide therapy while managing challenging behaviors. Having a good baseline knowledge about factors that contribute to challenging behaviors as well as specific

strategies and interventions is imperative for success. Challenging behaviors can impact many aspects of a child's life with DS. Implementing a plan that suits the individual child's needs is essential. Providing resources and recommendations strategies for parents regarding behavior management is also a crucial aspect of intervention. Many sources have determined strategies and interventions to be successful within populations such as ASD, but there is not as much research regarding the DS population only. This especially is important for implementing behavioral interventions such as ABA and PTR. After completing research, it is evident that more research is warranted for children with DS regarding challenging behaviors.

Challenging Behavior Tips for the Speech-language pathologist (SLP) By: Emily Sproat

Be Consistent

While in therapy it is important to set expectations and then follow through with them. This includes therapy and behavioral activities.



Listen

As the SLP, it is important to listen to what the child is saying, this could help facilitate further communication.

Incorporate Visuals

Using visuals such as a schedule, social stories or a pacing board can help a child stay focused on the task at hand.

Provide choices

In therapy sessions, provide options within reason can help the child take ownership of their skills as well as provide extra motivation.

Use Favored materials

Materials that are preferred by the child can help elicit more trials. They could also become a behavioral reinforcer.

Adapt therapy room

Altering the seating arrangement or placing toys in specific areas could help deter challenging behaviors if they arise.

Resources

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