The Occurrence of Fluency Disorders in Individuals with Down Syndrome and Autism Spectrum Disorders

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“The Occurrence of Fluency Disorders in Individuals with Down Syndrome and Autism Spectrum Disorders”

Honors Research Project

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Abstract

Including a comprehensive literature review of research studies in fluency disorders, this project will aim to observe how stuttering and fluency disorders affects individuals with Down Syndrome and Autism Spectrum Disorders. The literature reviews will include case studies where the goal was to add techniques to everyday speech which reduced the overall occurrence of stuttering behavior and the negative psychosocial impacts on the individuals in the case studies. After thorough review of the case studies and other related literature, two surveys will be developed for possible administration to caretakers for people with Down Syndrome and Autism Spectrum Disorders who stutter and the individuals themselves.

Introduction

Fluency is the ease with which people are able to verbally communicate in a smooth manner. The term “fluency disorders” encompasses both stuttering and cluttering behaviors. Stuttering is characterized by repetition of sounds, syllables, words and phrases, prolongation of sounds, blocks, interjections, and revisions that can affect the way one produces their speech. It usually is presented in childhood, though children and adults can both be affected by stuttering. Cluttering is characterized by the deletion or collapsing of syllables, causing periodically unintelligible speech patterns. The words being spoken are difficult to understand because sounds in different words are put together with a rapid rate of speech (“Childhood Fluency Disorders”). All speakers may have moments of “typical disfluencies”, or moments when they may use fillers (“um”, “uh”, “so”, “like”), these moments are not atypical. Dysfluency is defined by repetitions, interjections, pauses, and revisions to speech. The most common fluency disorder is stuttering, and it is the fluency disorder that will be primarily investigated during this study (American Speech-Language-Hearing Association).
**Explanation of Fluency Disorders**

A fluency disorder occurs when moments of disfluency are accompanied by a rate of speaking that may be unusual, use a disrupted rhythm, and may include repetition of sounds, syllables, words or phrases, blocks, or the prolongation of sounds (*American Speech-Language-Hearing Association*). Among typically developing people, 5% of preschool aged children and 1% of the general population is affected by stuttering. Despite this, fluency disorders are not associated with any disorder of the brain. Similarly, about 5% of the population claims to have stuttered at some point for about 6 months. It is known, however, that men are more likely to have a stutter than women.

It is largely a phenomenon lacking adequate explanation of the etiology. Most recently, the research on neural bases regarding fluency disorders has reported less myelinated white matter strength along some parts of the left arcuate/superior longitudinal fasciculus in all people who stutter who participated in this study (Soo-Eun, Garnett, Etchell, and Chow, 2019, pg. 568).
Fluency Disorders and DS/ASD

**Figure 1:** Major intrahemisphere white fiber tracts of the brain (*Annals of Indian Academy of Neurology*)

This pathway is often referred to as the dorsal auditory tract which connects the motor areas for speech to the auditory areas of the brain which help people to process speech sounds needed to efficiently articulate speech sounds. This region of the brain helps the speaker to listen, process, and produce the speech necessary to respond (Soo-Eun, Garnett, Etchell, and Chow, 2019, pg. 269).

Fluency disorders are one of the most recognizable speech disorders because the repetition of sounds or words, prolongation of sounds, and blocks can be identified even without knowledge of other characteristics of fluency disorders.

Stuttering can be developmental or acquired. When it is acquired, it typically happens as a result of psychological trauma, a neurological disease, or a brain injury; however, developmental stuttering accounts of a majority of stuttering cases. Developmental stuttering has an onset before age 7 and is not associated with psychological or physical trauma (Gillam & Marquardt, 2016, pg. 196).

**Figure 2:** The table above distinguishes differences between developmental stuttering and acquired stuttering (Gillam & Marquardt, 2016, pg. 196)
When speaking about the characteristics of stuttering, there are different terms that are used. The primary stuttering behaviors include prolongations, repetitions, and blocks. An example of a repetition might include saying “S-s-s-speech” rather than “speech” or repeating one sound more than once any place in a word. Prolongations occur when a certain speech sound is drawn out for longer than what is normal. For example, drawing out the /f/ sound when saying the word “found”. Blocks are another characteristic defined as a primary stuttering behavior. It is inaudible compared to prolongations or repetitions and could be described more accurately as silent blocks. (Gillam & Marquardt, 2016, pg. 198). Secondary stuttering behaviors are the behaviors that accompany the effects of primary stuttering behaviors. For example, during a block, someone might close their eyes, purse their lips, insert “uh”, or change words (Gillam & Marquardt, 2016, pg. 199).

People who stutter do not all display the same characteristics of stuttering. Some people who stutter might rarely have periods of time where they do not stutter, while others might have very fluent periods mixed with disfluent periods of time (Gillam & Marquardt, 2016, pg. 200).
Figure 3 (above): The table lists internal effects and environmental opportunities for socialization along with the way a speech-language pathologist might assess their behaviors in these settings (Gillam & Marquardt, 2016, pg. 215).

People who stutter typically report feeling more comfortable in social situations following their treatment with a speech pathologist. The most common treatments for fluency disorders include stuttering modification and fluency shaping. Stuttering modification are techniques used by the person who stutters that help them to modify stuttering to be less tense and more relaxed, giving it a somewhat natural feel and reducing the stress that might result from stuttering (Gillam & Marquardt, 2016, pg. 219). Fluency shaping is a therapy technique that
some speech pathologists use to reduce the frequency of stuttering all together (Gillam & Marquardt, 2016, pg. 221).

<table>
<thead>
<tr>
<th><strong>Stuttering Modification</strong></th>
<th><strong>Fluency Shaping</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Client is taught to stutter less and more easily.</td>
<td>Client is taught to have stutter-free speech.</td>
</tr>
<tr>
<td>Speech is more natural.</td>
<td>Loss of speech naturalness.</td>
</tr>
<tr>
<td>Considerable focus on attitudes and negative reactions to speaking situations.</td>
<td>Little to no attention given to attitudes, negative reactions, and so on.</td>
</tr>
</tbody>
</table>

**Figure 4 (above):** The differences between stuttering modification and fluency shaping focus on the attitudes and emotions surrounding stuttering. Many clinicians tend to use a combination of techniques from both types of therapy to create and treatment plan that fits their clients’ needs (Gillam & Marquardt, 2016, pg. 219).

**An Introduction to Down Syndrome**

Down Syndrome (DS) occurs in about 1 in 700 babies born and is a result of a full or partial copy of chromosome 21. Among many other physical attributes displayed by individuals with DS, speech and language are two of the most observable abnormalities present in individuals with DS. Some of the main causes of disordered language in individuals with DS include cognitive impairment, impaired short-term memory, impaired quality of mother-child interaction, developmental delay, neurological disorders of the stomatognathic system, and auditory and visual impairments. It also sometimes results in later development of speech. The number of words or length of their social interactions also displays some impairments and deviations from what is normal (Seno, Giacheti, & Moretti-Ferreira, 2014, pg. 1314).
Speech and Language for Individuals with Down Syndrome

The physical abnormalities present in those with Down Syndrome allow them to have access to intervention relatively easy from an early age. Parents to children with DS often are aware that their child will have DS before the child is born. This also improves the access families have to early intervention services. Children with DS are thought to be slower at developing what is considered typical speech and language skills. Receptive and expressive language understanding is often behind more than vocabulary itself, and phoneme development is also more delayed than general understanding of individual words (Eggers, K., & Van Eerdenbrugh, S., 2018, pg. 73). The number of words or length of their social interactions also displays some impairments and deviations from what is normal. (Seno, Giacheti, & Moretti-Ferreira, 2014, pg. 1315). Though the official percentage is unclear, it is estimated that the prevalence of stuttering in people with DS ranges from 21% to 48%, and often coexists with other speech and language impairments. Some of the most common speech errors in children with Down Syndrome include cluster reductions, final consonant deletion, and the use of stops for fricatives. Stuttering is often observed in individuals with Down Syndrome, but it is important to note that fluency disorders are not typical features of people with Down Syndrome (Eggers & Van Eerdenbrugh, 2018, pg. 73).

The Treatment of Fluency Disorders in Individuals with Down Syndrome – Case Study

Summary

Fluency disorders can make communication difficult for people with DS. These disfluencies are often treated by a teaching slow rates of speech, along with phrasing and pausing techniques when speaking. Other treatments for stuttering that are used for typically developing individuals in speech therapy include “easy onset” where the individual eases into the sounds in
the initial place in a word. This is not widely used when treating a person with DS because it could cause frustration or shame of stuttering in those individuals. However, many treatment plans for individuals who stutter and do not also present with DS, clinicians must also consider comprehensive treatment: children who stutter could suffer from anxiety or depression. Two common modifications made to speech disfluencies include tension and timing. Timing can be described as a slower rate of speaking. When this technique is used, syllables are drawn out and there might be longer gaps between words when speaking (Eggers & Van Eerdenbrugh, 2018, pg. 80). This helps the speaker to organize their speech and appear more fluent. Therapy helps the speaker to reach a point where timing is appropriate for the speech setting and it does not sound too slow or unnatural. When speech does not feel or sound natural, the client is less likely to use techniques in their day-to-day life. Tension can be reduced in a couple of ways. The most common way that a speech pathologist will teach a reduction of tension when speaking is by using “easy onset”. When using “easy onset”, physical tension in the articulators of the oral cavity are reduced. This prevents tension from having a chance to build up in general (Eggers & Van Eerdenbrugh, 2018, pg. 81).

In a case study completed by researchers in communication sciences and disorders, an 8-year-old girl stuttered anywhere from 29.8% syllables stuttered during a reading sample to 54.7% syllables stuttered in a conversational setting before treatment. Her stuttering included part word repetitions, silent prolongations, and audible prolongations. Evidence of stuttering as secondary behaviors included visible lip tension and open mouth during moments of disfluency. These stuttering behaviors had profound effects on her life at home and at school. The behaviors were a large source of frustration and avoidance of social settings. She had presented with speech and language delays in the past but never received therapy for stuttering. Formal speech and
language screenings placed her in moderate to severe categories for receptive and expressive language. Despite obvious challenges associated with these stuttering behaviors, her speech was generally intelligible. She had been to speech therapy before for articulatory disorders and expressive/receptive language skills. The young girl’s treatment was based off of the Comprehensive Stuttering Program for School-Aged Children. This program specifically targets social and emotional aspects of stuttering as well as the stuttering behaviors. It also allows parents to deliver some parts of the therapy at home to help the client to have a better outcome with therapy (Harasym & Langevin, 2012, pg. 254). The six phases of this case study are shown below. The number and name of the phase can be found on the left side of the chart, while components of each stage are found on the right side.
Figure 5 (above): Overview of Treatment Plan for Case Study with 8-year-old female (Harasym & Langevin, 2012, pg. 255)

The entire treatment program took place over 17 months. Throughout the course of treatment, the client learned how to prolong speech sounds and use 40-60 syllables per minute as well as other techniques such as easy breathing, smooth blending, and light touches; the young girl and her mother also attended treatment sessions together where the young girl worked up to 60-90 syllables per minute. With the reinforcement of therapy techniques at home with her mother, the client was able to practice her speech and the techniques in the clinic and allow the
clinicians to evaluate her progress throughout the course of treatment. Her behavior was reinforced by her mother, and her mother rated the client’s speech at the end of every day so that the clinicians could track her progress. In phase II specifically, the client was taught the “3T’s skill”, which intensify skills of speaking in different settings. The 3T skills include “Think before speaking, take time to breathe, and talk using fluency skills” (Harasym & Langevin, 2012, pg. 256).

Eventually her speech rates increased to 90-120 syllables per minute in more than one setting. These settings often included different conversational partners in various settings.

![Graph](image)

**Figure 6 (above):** The graph above illustrates the percentage of syllables stuttered in conversation, reading, and during a home sample before treatment, after treatment, and in a follow-up session after the initial post-treatment session. There was a significant decrease in the syllables stuttered post-treatment, and then again at the follow-up (Harasym & Langevin, 2012, pg. 258).
Figure 7 (above): The graph provides an illustration comparing the syllables spoken per minute before treatment, after treatment, and in a follow-up session. The syllables spoken per minute increased greatly from the pre-treatment stage to the post-treatment stage, and then again at the follow up (Harasym & Langevin, 2012, pg. 258).

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-treatment</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much stuttering interferes with or affects:</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Talking with friends</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Making new friends</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>School work</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Talking with family</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>How much stuttering bothers you</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>How much you worry about your stuttering</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>

Note: Response options range from 0 to 6 with 0 = not at all, 1-2 = a little bit, 3-4 = quite a bit, and 5-6 = a lot.

Figure 8 (above): The client rated the items in the chart above before treatment and during her follow-up session. Before treatment, every category was rated by the client as being a 6. While most of the items improved in scoring by the follow-up, talking with friends was rated as a 2 and her stuttering still affected her schoolwork. The program seemed to be effective in many different aspects of the client’s life, but the occurrence of her fluency disorder did still have some effects on the client’s life (Harasym & Langevin, 2012, pg. 259).
Figure 9 (above): After the treatment, the mother of the client as well as the client responded to different items regarding how they felt about the effectiveness of the treatment over the 17-month span. The mother seemed to report significant improvements in the conversational ability when managing fluency in her child. The client herself seemed to feel that her self-confidence improved, and she used her skills outside of the clinic “most of the time” (Harasym & Langevin, 2012, pg. 259).

<table>
<thead>
<tr>
<th>Item</th>
<th>Parent</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-confidence</td>
<td>Greatly improved</td>
<td>Greatly improved</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>Greatly improved</td>
<td>n/a</td>
</tr>
<tr>
<td>Anxiety</td>
<td>No anxiety</td>
<td>n/a</td>
</tr>
<tr>
<td>Participation</td>
<td>Improved (sometimes participated previously, now often participates)</td>
<td>n/a</td>
</tr>
<tr>
<td>Enjoyment of therapy</td>
<td>Always enjoyed</td>
<td>n/a</td>
</tr>
<tr>
<td>Use of skills outside of clinic</td>
<td>Most of the time</td>
<td>Most of the time</td>
</tr>
</tbody>
</table>

Note: Response options were “never”, “sometimes”, “often”, and “always”.

Figure 10 (above): The teacher’s evaluation of speech fluency compares the client’s stuttering behaviors before treatment and after treatment (Harasym & Langevin, 2012, pg. 260).

Through the use of a treatment plan that involved in-person speech therapy with clinicians and some parent administered fluency shaping techniques over a 17-month span, the client showed significant improvements in her fluency, confidence in social settings, anxiety when speaking, participation in social settings, self-corrective abilities, and general self-esteem. The client enjoyed the treatment and felt that it had an overall positive impact on her self-esteem, confidence, and ability to transfer skills to settings outside of therapy. Her mother felt that the
stuttering behaviors that remained after treatment were significantly less severe than when she first began treatment (Harasym & Langevin, 2012, pg. 261). The overall effects that this treatment plan had on her life were positive. As a whole, the study concludes that fluency shaping could be an effective treatment option for children with DS who stutter.

**An Introduction to Autism Spectrum Disorders**

Autism Spectrum Disorder (ASD) is a developmental disability defined by a very wide range of social, behavioral, and communicative challenges. The behaviors that people with ASD present might be different than the ways most other people might communicate or act in various settings. Some examples of behaviors that people with ASD might display include avoiding eye contact, trouble expressing wants or needs, repetition of actions or phrases, sensory overload, trouble adapting to change, trouble understanding the feelings of others, or no interest in others in general. People with ASD do not have any distinguishing physical features, making early detection and early intervention difficult. The diagnosis of ASD can be a tedious process. It involves a series of screenings and tests which allow a team of professionals to effectively diagnose a child with ASD. It can take many years for an autism diagnosis to be reliable. Early detection is important should the child need specific interventions in speech, language, or other skills (Centers for Disease Control and Prevention).

**Speech and Language for Individuals with Autism Spectrum Disorders**

When observing and evaluating children and adults with ASD it is important to understand the differences in speech and language development between typically developing people and people with ASD. Pragmatic abilities are often impaired in people with ASD. More specifically, these individuals have shown more difficulty in answering questions and making a personal request. They often test well and present a good understanding of overall language, but
consistently show deficits in pragmatic language, or language in social settings. One particularly difficult area of pragmatic language that often presents some difficulty is the understanding of emotions conveyed in speech.

People with ASD can present with disfluency anywhere from less than 2% of the time to 20% of the time. This difficulty in communication resulting from stuttering or disfluent behavior as well as other language difficulties can cause negative psychosocial feelings in people with ASD. Many individuals with ASD present more than one speech or language disorder. It is for this reason that fluency disorders are difficult to diagnose in children with autism due to the various communication disorders that can present themselves in children and adults with Autism Spectrum disorders (Scott, Tetnowski, Flaitz & Yaruss, 2013, pg. 75-76).

**The Treatment of Fluency Disorders in Individuals with Autism Spectrum Disorder – Case Study Summary**

In a case study involving a 21-year-old man with ASD, percentage of stuttered words was calculated and analyzed in multiple conversational settings. Some background on the 21-year-old with ASD includes that his official diagnosis at age 16 was Asperger’s syndrome (AS). AS is a developmental disorder on the autism spectrum that is characterized by exceptional or below average language abilities and repetitive or lack of patterns in behaviors and language (*National Institute of Neurological Disorders and Stroke*). Occasionally, the settings which occurred outside of the clinical sessions. The preliminary speech sample concluded that stuttering occurred on 15.75% of spoken syllables and was paired with a lack of awareness in his stuttering behaviors as a baseline for treatment. This number indicated that he had a severe stutter. However, he also presented with deficits in receptive and pragmatic language and weak social skills. In order for his stuttering to be effectively treated, he needed improved social-pragmatic
language (Brundage, Whelan, and Burgees, 2013). The clinicians believed that, to some extent, his stuttering behaviors were related to behavioral deficits in social settings. For many people with autism this is true. In order for therapy, which provides techniques for fluent speaking to be effective in people with ASD, the individual must first receive therapy for social-pragmatic deficits. To understand the social skills and behavioral traits for this individual, The Clinical Evaluation of Language Fundamentals- Fourth edition (CELF-4) and the Vineland Adaptive Behavior Scales- Second Edition (VinelandTM-II) were administered to the client.

<table>
<thead>
<tr>
<th>CELF-4 language index</th>
<th>Standard score</th>
<th>Percentile rank</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core language index</td>
<td>79</td>
<td>8</td>
<td>BNL</td>
</tr>
<tr>
<td>Receptive language</td>
<td>72</td>
<td>3</td>
<td>BNL</td>
</tr>
<tr>
<td>Expressive language</td>
<td>108</td>
<td>70</td>
<td>WNL</td>
</tr>
<tr>
<td>Language content</td>
<td>100</td>
<td>50</td>
<td>WNL</td>
</tr>
<tr>
<td>Language memory</td>
<td>99</td>
<td>47</td>
<td>WNL</td>
</tr>
<tr>
<td>Working memory</td>
<td>94</td>
<td>34</td>
<td>WNL</td>
</tr>
</tbody>
</table>

BNL below normal limits, WNL within normal limits

**Figure 11 (above):** Clinical Evaluation of language fundamentals for 21-year-old in case study (Brundage, Whelan, and Burgees, 2013, pg. 484)

The CELF-4 is used to screen for and identify a language disorder in individuals ages 5 to 21 years-old. It helps clinicians to identify the level of severity of a language disorder and help to also identify different strengths and weaknesses. It is used to make recommendations for intervention and the intensity of services that might be needed for language disorders. It is comprised of 18 subtests within four levels of testing, each assessing different aspects of language including language quality and content (Pearson Learning, 2013).
Figure 12 (above): Vineland Adaptive Behavior Scales- Second Edition (Brundage, Whelan, and Burgees, 2013, pg. 485)

The VinelandTM-II assess daily living skills, some motor skills, and socialization along with communication skills. It helps to measure the different mild to severe impairments that people with ASD sometimes present with, including motor skills, behavior, and activities of daily living. Its main goal is to diagnose and classify intellectual and developmental disabilities. It helps to provide documentation for qualification of services for special education or other interventions that might be needed for intellectual, behavioral, or emotional development. It can be used for anyone aged 3-22 years old and is administered individually through a norm-referenced format. There are 4 domains, 10 subdomains, and some maladaptive behavior scales. It takes anywhere from 20-60 minutes to administer (TSLAT).

The CELF-4 and VinelandTM-II scores were important because social-pragmatic language was screened for and treated before intervention for fluency began. It remained a large part of the treatment for the client because the clinicians needed to ensure that the percentage of stuttered words did not decrease because of changes in treatment for social-pragmatic deficits, but because
of the effectiveness of the stuttering treatment program (Brundage, Whelan, and Burgees, 2013, pg. 485).

In order to evaluate when the stuttering was occurring behaviorally in the individual, samples of conversation including 400-500 words were collected to determine what percent of syllables were stuttered. These could include part-word repetitions, sound prolongations, and air being blocked within the vocal tract that may sound like single syllable word repetitions. After this was done, the client engaged in a conversational probe at the word-level, sentence-level, and conversational level to establish a baseline for how many words he was stuttering on. Next, listeners who did not know the client were brought in to engage in conversation with the client. This way the clinicians were able to observe whether or not his fluency skills were general for all conversational settings or not, and then they were able to adapt their treatment and study accordingly. While this was happening, the client was also receiving treatment for social-pragmatic language, with goals including increasing the client’s awareness of nonverbal communication and associating these skills with emotions, as well as thinking of new perspectives with conversational partners. His treatment was intensive, including fifty-minute therapy sessions twice a week, where half of the session was dedicated to stuttering therapy and half was dedicated to pragmatic skill shaping (Brundage, Whelan, and Burgees, 2013, pg. 485).

The treatment for stuttering that the client was receiving was based on the fluency rules program (FRP). This program’s goal is to help the clients to stutter less by teaching speaking rules to diminish the behavior. Some of these skills include “speaking slowly and making sure to say every word only once” (Brundage, Whelan, and Burgees, 2013, pg. 485). Despite speaking more slowly, there is little effect on the conversational rate of speech, meaning that it does not sound slower or abnormal for a normal conversational setting.
Treatment for stuttering began at the word-level. When the client was able to successfully say one word fluently, he was able to move on to two words. He continued sequentially in this way until he reached five words. At that point, the client moved to the sentence-level with two-word sentences, moving numerically until he was comfortable with multiple-word sentences. After reaching that milestone, the client was asked to talk for different intervals of time in a fluent manner. The therapy was recorded and evaluated for fluency by using an Olympus Digital Voice recorder when the client was not inside of the clinic and a Marantz CD when the client was inside of the clinic. This software gathered data on disordered fluency such as blocks, sound prolongations, and part-word repetitions (Brundage, Whelan, and Burgees, 2013, pg. 486).

Throughout treatment, the client showed more responsiveness in “rule-based learning, attention to task, and working memory” (Brundage, Whelan, and Burgees, 2013, pg. 485). The areas of difficulty for the client continued to be a lack of awareness of the emotions of others and himself in social settings.

Before intervention began, the client was stuttering upwards of 14.57% of the words he spoke with a standard deviation of 3.73. The general trend of his baseline screening was that his stuttering behavior was increasing, signaling more severe stuttering. During the phase of the study were FRP was introduced, the general trend of the client’s speech was a downward trend in conversational probes to about 8.82% of spoken words stuttered at the one-word level. The treatment phase provided more of a downward trend signaling less severe stuttering behaviors. Introducing the client to sentence and conversational levels during treatment showed even more of a decrease in %SW to about only 3.95% with a standard deviation of 2.75 within the clinic, and even fewer stuttering behaviors outside of the clinic. The percentages that were recorded as the results reflect the trend of a stutter in the mild range.
The results of the study show some promise in using FRP as a form of treatment for the co-occurrence of ASD and stuttering. The participant in the case study displayed little awareness of the stuttering behaviors as well as the other deficits in social language. Despite this, he was still able to yield successful results from his treatment and participation in his intervention (Brundage, Whelan, and Burgees, 2013, pg. 487).

**Survey Questions**

Based off of the information collected through this project, some important questions for a potential survey to gather more data on this topic arose. The survey questions would provide objective feedback based on how families and caretakers perceive fluency disorders are affecting their loved one’s life. These responses can help a clinician to construct a therapy plan that is also family centered, since they are potentially the most common conversation partners for people who stutter with DS and ASD. This information would also help to evaluate the possibility of these fluency disorders being more common in one or both of these developmental disabilities, and which developmental disability presents more often with fluency disorders. A clearer understanding of which developmental disability is more likely to present with fluency disorders could help establish a more universal evidence-based practice for all clinicians to use as the basis for their treatment. The survey for caretakers can be found below:
Parent/Caretaker Survey

1. Does the individual for whom you provide care have an Autism Spectrum Disorder or Down Syndrome?
   a. Autism Spectrum Disorder
   b. Down Syndrome

2. Does this individual appear to have a stutter when they speak? i.e. repeating words, phrases, or sounds more than once when speaking
   a. Yes
   b. No

3. If yes to the question above, rate on a scale of 1 to 5 how much it affects their ability to communicate (1=does not affect their ability to communicate, 3= moderately affects their ability to communicate, 5= severely affects their ability to communicate).
   1  2  3  4  5

4. Does their stuttering include any of the following? (Check all that apply)
   o Prolongations - certain speech sounds are drawn out for longer than what is normal
   o Repetitions - repeating one sound more than once in a word
   o Blocks – inaudible, but obvious pause in the middle of a sentence or word on one specific sound

5. How often does their stuttering occur, on average?
   a. Always
   b. Multiple times a day
   c. A few times a day
d. Sometimes (once a day or every few days)

e. Never

6. Does the individual you provide care for attend speech therapy?

a. Yes

b. No
Furthermore, the next survey questions could be administered to people with DS and ASD before any intervention takes place to have a better understanding of how they perceive their own stuttering behaviors. A certain level of cognition would need to be determined before this survey could be administered, since both developmental disabilities could present with a wide range of cognitive abilities. Screening for a general understanding of these questions could be done through the CELF-4, which was used during the case study with the man with ASD. If the adaptive levels for expressive and receptive communication were within normal limits, the individual would likely have enough understanding of language to adequately answer these questions. Age would also be a factor in the individual’s ability to read the questions themselves or have the questions read to them.
Self-Evaluation for Person Who Stutters

1. How comfortable are you in your ability to communicate clearly with others?
   a. Always comfortable
   b. Sometimes comfortable
   c. Neutral
   d. Usually uncomfortable
   e. Always uncomfortable

2. When you are talking to others, do you feel that others have some difficulty understanding you?
   a. Yes
   b. No

3. Do you think that you stutter when you speak?
   a. Yes
   b. No

4. If yes to #3, rate on a scale from 1-10 how seriously this stuttering affects communication abilities (1 – not at all, 5 – somewhat affects ability to communicate, 10 – profound negative impact on ability to communicate)?

   1  2  3  4  5  6  7  8  9  10

5. How often do you stutter when you speak?
   a. Always (multiple times a day)
   b. Sometimes (occasionally in conversation)
   c. Rarely (5 times a day or less)
   d. Never
These questions could help to understand how people with ASD and DS perceive their ability to communicate. In the future, these results could help when designing a treatment plan for fluency disorders in these populations. By having a clear understanding of the speaker’s own perceptions of their speech abilities, speech-language pathologists can create a personal therapy plan that considers comfort levels and perceptions of the client.

Considerations for Treatment of Fluency Disorders and Communication with Individuals with ASD and DS Who Stutter

Individuals with Down Syndrome and Autism Spectrum Disorders present a wide range of delays and impairments in speech and language. Many times, when screening for, diagnosing, or treating a fluency disorder, there are coexisting disorders that must be treated in a specific order, but in some cases, can be treated together. There is a large number of personal and emotional aspects of stuttering that should also be evaluated. It is important to involve the family in treatment, as there are benefits to a more family-centered approach as displayed by the case studies evaluated. The caretakers often know communication patterns to recognize during conversation with the person they provide care for and implement techniques from therapy in everyday conversational settings.

People who stutter often report feeling a sense of frustration by their speech disorder. They can sometimes feel like they are not in control of their ability to communicate, leading to an avoidance of social situations all together.
Table 13 (above): The image above provides general advice for interacting with people who stutter (Gillam & Marquardt, 2016, pg. 211).

**Conclusion**

In conclusion, fluency disorders affect more than just the ability to communicate. In these two case studies, there was evidence of psychological effects, as well as other language disorders that required treatment.

When evaluating the occurrence of stuttering and ASD, we know that they can co-occur in some cases. Despite this fact, speech-language pathologists are still trying to figure out the best treatment for both disorders at the same time. Fluency Rules Program (FRP) proved to be successful in the treatment for this individual in the specific case study above with the man with Asperger’s Syndrome. In order for a better understanding of the success of this type of treatment in anyone with ASD or AS, a more comprehensive study on an entire group of people with ASD would need to occur. They would likely need to have various diagnoses on the autism spectrum and present with any degree of stuttering. Although it was successful in one specific case, in order for it to become evidence-based practice, it would need more sufficient evidence proving its effectiveness for a large group of people.

Similarly, when treating an individual with DS, it is important to evaluate the abilities of the individual before implementing a therapy plan. Since some techniques for stuttering therapy
might cause frustration in individuals with DS, working with the family to provide and implement effective therapy is crucial to successful outcomes of any therapy plan. The therapy techniques used in the case study with the young girl with DS took place over 17 months with a six-phase process. This process took place both in a clinic and at home. She gradually increased the syllables she used through reinforcement at home and techniques learned in the clinic such as easy breathing, smooth blending of sounds and syllables, and voluntary prolongation. The successful outcome of this study was measured by the primary caretaker, the teacher of the young girl, and the young girl. Once again, a case study provides the effectiveness of the therapy techniques on one individual. To provide a more thorough understanding of how this therapy plan could improve fluency skills in other individuals with DS, a more comprehensive study would be necessary. Since there are various language and speech abilities for people with DS, and severity of stuttering might differ from person to person, it would need more successful outcomes in order to become evidence-based practice in therapy for people who stutter.

It is important to understand that the goal of speech therapy for fluency disorders does not have a basis in “curing” or “fixing” the fluency disorder itself, but rather helping the client to communicate in a way that they are comfortable. There are many psychosocial aspects of stuttering which make communication between a person who stutters and a person who does not stutter difficult at times. The emotions felt by the person who stutters can be strong. There is an added layer of emotions and difficulty communicating when the person who stutters also presents with a developmental disability.

When treating anyone with a developmental disability, having an understanding of their level of functioning is important before implementing any therapy plan, even if there is a suspected speech or language disorder. Both of these research case studies would need more
sufficient evidence proving their effectiveness within a larger study before becoming common practice within the field of speech pathology.

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