

2021

## Exploring the Diagnostic Journey of a Preschool-Aged Female: A Retrospective Case Study

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**EXPLORING THE DIAGNOSTIC JOURNEY OF A PRESCHOOL-AGED FEMALE: A  
RETROSPECTIVE CASE STUDY**

A Thesis

Presented to

The Faculty of the Center for Communication Disorders

Murray State University

Murray, KY

In Partial Fulfillment

of the Requirements for the Degree

of Master of Science in Speech-Language Pathology

by Lindsay Crafton

May 2021

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## Acknowledgements

Over the past two years, I have received a great amount of guidance and support in the creation of my thesis. I would first like to thank Dr. Stephanie Schaaf for agreeing to be my advisor for a second time. You will never know how much I value your mentorship and friendship. You have been my rock through graduate school and this paper would not have even been started without your support and direction. Thank you for pushing me out of my box, providing endless suggestions, and helping me discover my potential. One day, I hope to be half as amazing as my role model.

I also want to thank Alison Brown and Amanda Duncan for serving on my committee, giving me advice, and being supportive throughout my research. Alison, I am beyond grateful for the wisdom and opportunities with which you have provided me over the past six years. Amanda, thank you for believing in me and helping me navigate my first graduate clinical experience. You were always accepting of my obsessively themed lesson plans and were there for me when I realized that no matter how much you plan, sessions may go differently. I admire you both and am grateful for all you have taught me.

Selecting my research topic would have been a lot more difficult without my participant and her family. Thank you for agreeing to participate in my study even amidst this crazy season of life. I am grateful for the opportunity to have worked with you all and further my knowledge in caregiver experiences with communication disorders.

To my family, friends, and Charlie; thank you for listening to my many “fun facts” about autism, letting me vent about having to write, and making me feel so accomplished upon the completion of this research. I could never ask for a better support system.

### **Abstract**

The purpose of this case study was to investigate the diagnostic route of a preschool-aged female initially suspected of having ASD with communication deficits and explore her journey to seek and receive services. In any diagnostic experience, it is imperative that caregivers understand the steps to seek appropriate evaluations and receive necessary services to improve their child's quality of life. While there are some systemic procedures in place aimed to identify children with communication disorders or other developmental concerns such as ASD early; the ultimate responsibility falls on the caregiver to follow up and follow through. Although diagnostic criteria for various communication disorders and ASD are outlined, diagnostic procedures and pathways for obtaining appropriate evaluations are not clearly defined nor outlined. In order to better identify and serve individuals with communication disorders and their families, barriers to appropriate diagnostic and intervention services should be identified. This retrospective case study outlines the process a preschool-aged female and her family went through to obtain her communication disorder diagnoses and intervention services. Findings recognize the significance of the caregiver's role in the process, identify barriers and successes in the process of early identification and intervention as well as explore discrepancies in diagnosis of ASD in females.

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## Chapter 1: Introduction

Communication impairments directly impact one's performance across academic, social, and professional settings (APA, 2013). A diagnosis of a communication disorder warrants intervention, treatment, and services. However, obtaining an appropriate evaluation and diagnosis can prove difficult. In order to better identify and serve individuals with communication disorders, such as autism spectrum disorder (ASD), barriers to appropriate diagnostic and intervention services should be identified. While the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) provides diagnostic criteria for ASD and other disorders related to communication, it does not provide a definitive route that one should take to seek evaluation and potentially receive a diagnosis (APA, 2013).

In addition to the uncertain diagnostic procedure, another barrier to obtaining an ASD diagnosis is the disparity found within the disorder. According to the *DSM-V*, there are four males diagnosed with ASD for every female (APA, 2013). There is not a clear explanation for this disproportionate ratio, but there are many possible factors that contribute to the misdiagnosis or lack thereof for females. Research shows that the presentation of symptoms can greatly differ between the two sexes (Bargiela, Steward, & Mandy, 2016; Cridland, Jones, Caputi, & Magee, 2013; Volkens, 2018). With varying restrictive, repetitive behaviors and strong masking abilities, females with ASD do not always fit the stereotypical expectations and definitions of autism that is portrayed in the media (Cridland et al., 2013). Since current diagnostic tools are most often normed on the more prevalent male population, screenings and assessments may not be inclusive of specific female characteristics. The disparity between sexes leads both professionals and

parents to question the validity and reliability of current procedures for referral, evaluation, and diagnosis of females with ASD.

A diagnosis of ASD or any communication disorder goes beyond assigning a label to an individual. When females are not provided with an appropriate diagnosis of ASD, they can experience a variety of emotions and adverse effects. Experiences may include a lack of identity, friendships, and opportunities due to communicative language impairments (Volkers, 2018). Once an adequate diagnosis has been made, appropriate evidence-based interventions can be implemented to target the communicative deficits (Bargiela et al., 2016). The “label” of autism spectrum disorders may also serve as an explanation for the individual regarding their personality, behaviors, and lifestyle. When the individual and their family truly understand the diagnosis, facets beyond interpersonal communication, such as a sense of self, confidence and other intrapersonal aspects can be addressed in order to improve the individual’s quality of life (Volkers, 2018).

The path to seeking and obtaining appropriate evaluations and referrals for necessary therapeutic services is not clear and consistent. Ideally, the process would begin with early developmental screenings completed by pediatricians (Centers for Disease Control and Prevention [CDC], 2018). If results indicate potential concern in regard to the child’s development, further evaluations by professionals, such as an autism specialist, speech-language pathologist, and psychologist, are recommended. Such recommendations are made to provide the child with access to early intervention services if deemed necessary.

While the process through referral, evaluation, and treatment is frequently guided by a pediatrician, the decision to pursue further evaluations and services is heavily dependent on the caregivers. Accessibility to services, whether it be through location or finances, plays a large role

in attaining a diagnosis and ultimately appropriate services as well. In other instances, parental concerns about developmental delays or deviations may not arise due to various reasons, including a possible lack of awareness or education on the characteristics and variability of the disorder or typical developmental milestones and developmental progression. If caregivers, pediatricians, or evaluators do not have any concerns, a diagnosis or lack thereof can be further prolonged. Still yet, serving as another dilemma is knowing when to accept what one professional has said over seeking second opinions.

The unclear nature of the ASD diagnostic process serves as a barrier to many families. Further research and guidance are needed to better identify, serve, and support individuals with ASD or communication disorders, in general. The purpose of this case study was to investigate the diagnostic route of a preschool-aged female initially suspected of having ASD with communication deficits and explore her journey to seek and receive services.

## Chapter 2: Review of the Literature

### Autism Spectrum Disorder

Autism spectrum disorder is a non-degenerative neurodevelopmental disorder characterized by pervasive social deficits and restricted, repetitive behaviors (APA, 2013). Before 2013, autism spectrum disorder (ASD) was divided into more specific disorders, including Asperger's disorder, autistic disorder, and pervasive developmental disorder - not otherwise specified (APA, 2000). The DSM-5 combined this group of disorders into autism spectrum disorder to note its wide range of characteristics. Characteristics of individuals on the spectrum can be quite diverse, including exceptional intelligence, varying independence skills, co-occurring disabilities, and even some who are nonverbal (APA, 2013).

Around 1% of the population has received a diagnosis of ASD (APA, 2013; American Speech-Language-Hearing Association (ASHA), 2020a). The incidence of ASD has been rising steadily since the 1960s, but it is unknown as to whether it is the result of increased awareness of the disorder, a true frequency increase, or other factors (ASHA, 2020a). When comparing the ratio of females to males with a formal diagnosis of ASD, there is a disparity of one to four (APA, 2013).

While specific etiologies for ASD have not been identified, there are a few presumed causes for the disorder. Research has indicated a link between ASD and genetic syndromes, brain-damaging infections, prenatal and perinatal issues, and other environmental factors (ASHA, 2020a; Centers for Disease Control and Prevention, 2018). In addition to emerging theories on etiology, there are known risk factors that are likely to contribute to ASD, but are not certainties. Environmental aspects such as older parental age or a low weight at birth may make individuals more susceptible to ASD (APA, 2013). With twin concordance studies such as that

completed by McKernan, Russo, Burnette, and Kates (2017), findings demonstrate that there is also a possible genetic factor for the etiology of ASD (APA, 2013). A fraction of cases are associated with a known genetic mutation, but even so, genetics cannot be fully responsible for the disorder at this time (APA, 2013). The consumption of prescription drugs valproic acid or thalidomide during pregnancy has also been linked to an increased risk of ASD (CDC, 2020a).

### *Characteristics of ASD*

Symptoms of ASD are typically recognized between 12 and 24 months of age but may be earlier if the disorder is more severe or later if milder. The main characteristics associated with ASD are deficits in reciprocal communication and interaction and restricted, repetitive patterns that impair overall functioning (APA, 2013). These communicative deficits may include difficulty with social pragmatic skills, expressive and receptive language, and cognition (ASHA, 2020a). Individuals diagnosed with ASD might also demonstrate impaired behavioral, emotional, and sensory regulation (CDC, 2020a). The diagnostic criteria for autism spectrum disorder include persistent social insufficiencies spanned across contexts, restrictive, repetitive behaviors and interests, present symptoms at an early age, impairments in current functioning, and the lack of a more suited disability (APA, 2013). Examples of such behaviors include very strict routines, displaying repetitive motions, experiencing delayed speech and language skills, resisting physical contact, preferring isolation from others, and having strong reactions to sensory input. The frequency and severity of diagnostic criteria present in an individual interfere with many facets of the affected individuals' daily lives. Learning can be impaired, aversions to change may be present, sensitivities may interfere with personal care, adaptive skills are inhibited, independence is difficult to establish, and executive function (decision making, self-regulation, etc.) is affected (APA, 2013).

### *Communication Disorders in ASD*

**Language Disorders.** Language is the process of expressing and receiving information through a shared conventional system, which can include written, spoken, or other communication modalities (ASHA, 2020c). Language can be broken down into five areas including phonology, morphology, syntax, semantics, and pragmatics. Phonology is the study of the speech sound system while morphology looks at how meaningful units of language are used. Syntax includes the rules that dictate how words can be combined, semantics refers to word meanings, and pragmatics is the social implication of language (ASHA, 2020c). With adequate knowledge and abilities in each of these domains, individuals are able to properly express and receive messages to and from others. A language disorder is a type of communication disorder characterized by difficulty in expressive or receptive language across any of the five domains (ASHA, 2020c).

Characteristics of a language disorder may be present in individuals with ASD or in the absence of another disorder, making the primary disorder that of language. Impairments may be seen in verbal and nonverbal communication from the time a child is first learning and using language and can continue for a lifetime. The symptoms and characteristics of a language disorder may change and vary in severity over spans of time (ASHA, 2020c; Psychology Today, 2018). Late language emergence (LLE), being a late talker, is a common initial diagnosis that may indicate a larger language problem. Factors that may contribute to LLE include family history of late talkers, male gender, low birth weight, socioeconomic status, and delayed motor development (Owens, 2018). A language delay in a young child does is not always indicative of a future language disorder. Language disorders can be diagnosed by a speech-language pathologist at a young age; however, some individuals may not receive a diagnosis until later in

their development. While language disorders may be diagnosed by speech-language pathologists at a young age, symptoms may not be apparent until later in life when complex language is more necessary (Psychology Today, 2018).

**Expressive Language Disorders.** Expressive language is used whenever an individual is relaying a message (ASHA, 2020c; Reed, 2012). The sender of a message must take an idea, implement proper language rules in formulating the message, and then transmit the information to a conversation partner verbally. Deficits in the process of encoding messages are known as expressive language disorders, a type of specific language impairments (SLI). For communication to be functional, an individual's expressive language should be purposeful, frequent, and flexible (Owens, 2018). Some of the common deficits within expressive language include difficulty with lexical retrieval, syntax, and morphology (ASHA, 2020c; Reed, 2012). Areas by which expressive abilities can be analyzed include, but are not limited to the abilities to combine sounds or words, utilize pragmatic functions, and repair communication breakdowns. Further, intelligibility, intent, and vocabulary can indicate the strength of one's expressive language skills (Owens, 2018).

**Receptive Language Disorders.** Opposite to expressive language, receptive language is the decoding of messages (ASHA, 2020c; Reed, 2012). It is generally accepted that individuals are more likely to have higher receptive skills than expressive. In children and adults alike, people are able to understand more information than they can formulate into words (Reed, 2012). A child's receptive abilities at a young age can correlate to their long-term language development as well as future receptive vocabulary and expressive complexity (Owens, 2018). Comprehension impairment is another area included in a receptive language disorder and can be related to deficits in semantics. Knowing the meanings of words and utterances is essential to

one's comprehensive abilities (Reed, 2012). The realm of receptive language consists of the ability or lack thereof to associate single and multiple word utterances to their referents, whether it be names, labels, actions, or functional words (Owens, 2018). Such difficulties in reception are often accompanied by those in production. While it has been thought by some professionals that comprehension difficulties can exist without coexisting expressive difficulties, there is not enough research to say whether or not this is the case (Reed, 2012).

**Pragmatic Language Disorder.** Pragmatics encompasses the functional aspects of language, such as the social implications of conversational exchanges (ASHA, 2020c; Reed, 2012). Discourse, the connected flow of language, and narrative, the recount of an event, are two essential pragmatic components within communication (Reed, 2012). Fluency and cohesion are also imperative aspects of pragmatic language. Without logical organization and fluid utterances, communication breakdowns can occur. When the inevitable breakdowns occur, the speaker must be able to repair the conversation and demonstrate communicative competence. In addition to the spoken domains of pragmatics, turn taking and appropriate use of nonverbal language are vital in effectively communicating (Reed, 2012). Pragmatic language is rule-governed yet varies depending on the context. Individuals with a pragmatic language disorder may exhibit any of the following symptoms: poor eye contact and engagement when being spoken to, unconventional use of gestures, deficiencies in joint attention, less initiation of interactions, and inability to relate with others (ASHA, 2020a; Reed, 2012).

**Contexts of a Language Disorder.** An individual with a language disorder may experience difficulty in many areas of life, such as engaging in conversation with others, following directions, forming adequate sentences, and even spelling words correctly (ASHA, 2020c). In 2001, the World Health Organization (WHO) published the International

Classification of Functioning (ICF) framework to be used in client-centered care (ASHA, 2020b). The ICF looks at all facets of life that any health-related condition may affect directly or indirectly. The two parts of the framework include “functioning and disability” and “contextual factors.” These are further broken down into “bodily functions and structures,” “activity and participation,” “environmental factors,” and “personal factors.” Each of these areas should be considered when assessing any individual with a disorder, including language. Having a comprehensive idea of the effects a condition has on an individual can be beneficial when treating the person holistically rather than treating the diagnosis, itself (ASHA, 2020). Various neurodevelopmental disorders such as autism spectrum disorder, attention deficit hyperactivity disorder, and learning disabilities may be associated with a language impairment (Psychology Today, 2018). Therapy from a speech-language pathologist can be implemented to stimulate development of language skills to encourage and improve communicative abilities (ASHA, 2020c).

## **Diagnosis**

Since ASD is a developmental disorder, symptoms are often present at a very early age. If symptoms are detected by caregivers early in a child’s life, the diagnosis of ASD can be very reliable by the age of two (Steiner et al., 2011). However, many individuals do not receive a diagnosis until preschool, elementary school, or much later in life (APA, 2013). Unlike other disorders, there is not a blood test or medical exam that can diagnose ASD (KATC, 2011). Instead, parental concerns are considered, and behaviors and development are analyzed to reach a diagnosis by medical professionals who have experience with autism spectrum disorders, such as developmental pediatricians, child neurologists, child psychiatrists, or child psychologists (Autism and Developmental Disabilities Monitoring Network [ADDMN], 2018).

### ***First Concerns***

According to an Autism and Developmental Disabilities Monitoring Network Community Report (2018), 85% of children diagnosed with ASD had documented concerns about development by the age of three. When concerns are noted, families can take their child to a pediatrician who can then make a referral to an autism specialist or psychologist. If the child is in school, families may also consult with their teacher to see if the at-home observations match up with those in an educational setting (KATC, 2011). For children under three years of age, state early intervention programs, such as Kentucky's First Steps, can be contacted to receive an evaluation to determine eligibility for services during the period of critical development (KATC, 2011). If language concerns arise first, a speech-language pathologist could be the first to implement treatment and intervention for symptoms of a pervasive disorder. Speech-language pathologists, physical therapists, occupational therapists, school personnel, mental health professionals, and dieticians may all be involved in treatment plans once a diagnosis has been made due to the presentation of a wide array of symptoms requiring a multi-disciplinary team (ASHA, 2020a; KATC, 2011). If caregivers do not recognize symptoms of ASD and go to the child's pediatrician, the disorder may be detected by the school district. Schools are responsible for identifying all children with disabilities in order to provide appropriate services (KATC, 2011).

### ***Diagnostic Components***

The process of diagnosing autism spectrum disorders should be comprehensive, including developmental screenings and comprehensive evaluations (CDC, 2020a). Developmental screenings can be performed by various professionals in educational and medical settings (CDC, 2020a). The CDC (2020b) explains that children should have standardized ASD screenings

completed at preventive care doctor visits at the ages of 18 and 24 months. Some potential screenings include the *Modified Checklist for Autism in Toddlers (M-CHAT)*, *Childhood Autism Rating Scale*, and the *Screening Tool for Autism in Toddlers and Young Children (STAT)*. If screening results indicate developmental issues, further evaluations are needed to appropriately diagnose ASD so that the child may receive appropriate intervention and services (CDC, 2020b). Once screenings show possible developmental deficits, more in-depth evaluations are necessary.

Evaluations can include observing the individual's behaviors, obtaining a case history, conducting parent or family interviews, behavioral observations, genetic testing, other medical testing, and standardized assessment tools designed for use with individuals with possible ASD (CDC, 2020a). Evaluations should be completed by a multidisciplinary team to ensure all bases are covered (ASHA, 2020a). An individual's diagnosis should include severity based on communication and behavior criteria separately to note how much support is needed by the individual in the respective deficit areas. Specifiers are also used in diagnosis to note co-occurring impairments and disorders (APA, 2013).

### ***Diagnostic Barriers***

Diagnostic difficulties can be caused by a variety of social contexts and structural barriers. Some of these factors include, but are not limited to inadequate screenings, lack of ASD awareness in parents and healthcare providers, or shortages of specialized diagnostic services for young children (Steiner et al., 2011; Martinez et al., 2018). Martinez et al. (2018) recognized the inefficiency in the journey of receiving a diagnosis of ASD and conducted a study on the diagnostic experiences of 450 families in regard to screenings, distance traveled to providers, and difficulty locating a provider. The researchers stated that the child's mean age when parents had their first concerns about their child's development was 20.6 months. However, the mean age at

diagnosis of ASD was 38.8 months. From the first parental concern to diagnosis, the mean range of delay was 19 months. It should also be noted that prior to receiving their diagnosis of ASD, over half of the children included in the study had been diagnosed with a different disorder while 25% were told that they did not have ASD (Martinez et al., 2018).

When considering possible barriers to diagnosis, Martinez et al. (2018) found that only 47% of participants had completed screening forms, 34% of families had difficulty locating a psychologist or psychiatrist for their child, and 8% had to travel further than 60 miles to receive their diagnosis. Results of the study suggest that the completion of screenings reduced the likelihood of diagnosis delay, however, it increased the likelihood of receiving shifting diagnoses, indicating problems with the sensitivity of screening instruments (Martinez et al., 2018). Additionally, it should be noted that overall, too few screenings are being administered. Despite the American Academy of Pediatrics recommending developmental screenings, it is evident that many pediatricians are not doing so. Further, those who are administering screenings may not have enough experience to be comfortable labeling children as “at-risk” for ASD (Lappé et al., 2018; Zuckerman et al., 2015). Therefore, it is implied that additional research regarding reliability, administration, and implication of diagnostic screenings is warranted.

**Accessibility and Expense.** Geographical and financial access serve as other predominant barriers to diagnosis of ASD. Residence in rural areas can influence the timeliness of an ASD diagnosis due to travel time and expenses that may be required to reach a physician or evaluation site (Lappé et al., 2018; Martinez et al., 2018). Additionally, there is a limited availability of healthcare providers that can diagnose ASD (Martinez et al., 2018). Many providers lack appropriate screening, referral, or diagnostic resources, while others experience a delay in obtaining or accessing such resources (Zuckerman et al., 2015). Consequently,

additional issues arise such as extensive waitlists, limited referral options, and requiring long distance travel to locate a provider. Accessibility could serve as a reinforcement for healthcare providers to downplay the severity of their concerns and under-refer families (Martinez et al., 2018; Zuckerman et al., 2015).

Even after a qualified and readily equipped provider is located, finances may then restrict access to diagnostic and treatment services. Numerous doctors visits and evaluations often lead to extensive medical bills despite having health insurance (Smith-Young et al., 2020; Martinez et al., 2018). When looking at factors correlated with shifting diagnoses before receiving one of ASD, Martinez et al. (2018) found that one of the strongest correlations was having public insurance rather than a private policy, suggesting that insurance coverage may serve as a concrete barrier for some families. The financial demands of ASD diagnostics justify findings that families with higher socioeconomic status are often more pleased with the diagnostic journey than those who do not have access to such financial means (Lappé et al., 2018; Smith-Young et al., 2018).

**Demographic Influence.** Additionally, demographics such as race, ethnicity, and gender further contribute to delays in diagnosis. Research indicates that Hispanic and African American children, children born outside of the United States, and children of parents with less formal education often receive a diagnosis of ASD much later than their counterparts (Lappé et al., 2018). Delayed diagnosis is common regardless of gender; however, research suggests that females are at an even greater disadvantage (Cridland et al., 2013; Mademtzi et al., 2018; Navot et al., 2017). Whether it is because of the different presentation of symptoms, social masking, or higher incidence of ASD in males, parents report having seemingly more difficulty in obtaining a diagnosis for their daughter than their friends with sons (Cridland et al., 2013).

Navot et al. (2017) completed interviews with mothers of females who reported that although they had early concerns, pediatricians were often skeptical about their daughters having ASD. Instead, the mothers were provided reassurance by the physician through statements including “She is a late bloomer,” “This is usually a boys’ thing,” or “She is only a little different,” indicating a lack of recognition of female presentations of ASD by pediatricians (Navot et al., 2017, p. 539). Whether due to lack of screenings, limited accessibility, or demographics, there are several barriers that may be faced by families seeking diagnostic services.

### ***Caregiver Role in Diagnosis and Treatment***

Caregivers play a vital role in obtaining a diagnosis and accessing treatment for ASD. When caregivers first notice their child’s atypical behaviors, they may view them as normal deviations from typical developmental milestones, reflecting their child’s personality (Lappé et al., 2018). Others may not have any concerns until a pediatrician or teacher brings light to the differences they are witnessing. As they receive advice from professionals and trusted peers about their child’s development, caregivers experience a variety of emotions, pressures, and conflicts about how to best care for their son or daughter. Since these individuals are often minors, it is ultimately up to the parents to decide whether or not to seek out additional advice, evaluations, and services (Lappé et al., 2018; Smith-Young et al., 2020).

Seeking out evaluations and a diagnosis or lack thereof can be stressful, expensive, and time-consuming (Lappé et al., 2018; Smith-Young et al., 2020). Compared to other diagnoses, the financial and employment burdens placed on families with a child with ASD are profound. More than half of the families included in a study by Smith-Young et al. (2020) indicated disruptions in employment due to child-care difficulties and other autism-related scenarios in the

past year. Some caregivers ultimately leave their jobs to meet the demands of childcare and appointments that compound stress (Lappé et al., 2018; Smith-Young et al., 2020).

In addition to emotional and financial demands, a diagnosis of ASD also warrants numerous appointments accompanied by potential extended time lapses between steps in the process. Lappé et al. (2018) and Smith-Young et al. (2020) conducted interviews with parents of children with a diagnosis of ASD in order to outline their experiences from initial concerns to accessing treatment. The consistent theme across parents was waiting. The time lapse between initial parental concern and diagnosis could range from months to years, generating a large delay in access to services and early intervention (Smith-Young et al., 2020). The initial period of wait began after identifying first concerns. Each family had to wait for appointments and referrals from healthcare providers to determine whether or not their concerns were legitimate. This period could include waiting for a referral to a child psychologist, being on a waitlist for the only local pediatrician, or waiting for an appointment only to have to schedule another meeting for the assessment to occur. An extended wait time brought some families to choose between continuing to wait to access diagnostics and intervention services covered by public insurance or paying more money out-of-pocket to access private providers in a timelier manner (Lappé et al., 2018; Smith-Young et al., 2020).

Two predominant factors that contribute to a caregiver's efficiency and satisfaction with an ASD diagnosis are advocacy skills and financial means. Smith-Young et al. (2020) looked at these factors and divided families into four main groups: advantaged advocates, restricted advocates, supported advocates, and driven advocates. Families who have high socioeconomic status (SES) are split into those with self-advocacy skills (advantaged) and those without (supported). Meanwhile, the families with lower SES are also split into groups with self-

advocacy skills (driven) and without (restricted). Without high SES and strong advocacy skills, it is likely that a diagnosis of ASD may be delayed or missed altogether. Families without adequate financial resources may be seen remortgaging their home or accruing credit card debt to get services for their child, while others may be unable to seek any services. Even if a family has the financial means to obtain diagnostic services, another dilemma arises if they are unable or unwilling to advocate for the child or are unsure where to start (Smith-Young et al., 2020).

Throughout the diagnostic journey, caregivers may face obstacles that require persistence to overcome. Parent interviews conducted by multiple researchers revealed that some families had been told to “wait and see” what would happen with their child’s development while others’ concerns were dismissed entirely, contributing to the diagnostic delay (Lappé et al., 2018; Navot et al., 2017; Smith-Young et al., 2020). Only when faced with educator concerns or maternal insistence did some providers pursue developmental evaluations (Navot et al., 2017). Providers may insist on testing for other disorders first and could even provide a false diagnosis of a related disorder instead of identifying ASD (Martinez et al., 2018). Obstacles during the diagnostic process may eventually lead to a family’s distrust in the healthcare system, leaving them unwilling to pursue further evaluations and support (Lappé et al., 2018).

**Path to Acquire Services.** Once a formal diagnosis has been given, the critical role of a caregiver continues along a new path to acquire services, therapies, and supports. ASD services exist across allied health professions in various domains, thus many parents take on the responsibility for coordinating a care plan for their child, which could include determining which service they believe would be most beneficial. Some may be comfortable with this undertaking, while others are unsure where to start and to what extent to engage with services (Lappé et al., 2018). Many of the diagnostic barriers present are reoccurring when seeking appropriate

intervention services. For example, families who live in rural areas and are located further away from services may need to relocate to other cities or school districts in order to have access to reliable services for their child (Lappé et al., 2018; Smith-Young et al., 2020).

### ***Educational Eligibility vs. Medical Diagnosis***

There are two types of ASD diagnoses: medical and educational (KATC, 2011). The medical diagnosis must be made by a psychologist, psychiatrist, or physician. The educational diagnosis is made by an evaluation team and admissions and release committee (ARC) in a school setting. The educational definition of ASD is focused on adverse impacts to educational performance and is used to determine if the individual qualifies for special education services under the *Individuals with Disabilities Education Act (IDEA)* (KATC, 2011). A medical diagnosis of ASD does not entitle individuals to special education services under IDEA, rather the inhibition of educational performance serves as the qualifier. Each state has its own definition and requirements for an educational diagnosis of ASD (IDEA, 2004). Kentucky requires that the school evaluation team determine that the individual meets criterion in Kentucky Regulatory Statute 157.200 to receive special instruction and services (KATC, 2011). Some of these necessary diagnostic characteristics are deficits in communication systems and social interactions, repetitive behaviors, and abnormal responses to stimuli. These deficits must not be the result of another disability or impairment. Just as a medical diagnosis does not warrant an educational diagnosis, educational diagnoses do not require a medical diagnosis (KATC, 2011).

### ***Comorbid Disorders and Differential Diagnosis***

An individual with a diagnosis of ASD can suffer from other disorders and impairments. Additional diagnoses of mental health, neurological, physical, or medical disorders can occur

alongside ASD and should be treated according to the individual's specific needs (KATC, 2011). These comorbid conditions become more prevalent during adolescence and adulthood (Trammell, Wilczynski, Dale, and McIntosh, 2013). With the possibility of comorbidity, comes the possibility of misdiagnosis. Due to misunderstanding of ASD diagnostic criteria, some symptoms may be mistaken as separate disorders rather than expressions of ASD (KATC, 2011). In order to determine appropriate treatment and services for the individual, it is important to note the difference in comorbid disorders and symptoms linked to ASD. Comorbid mental disorders may be present when an individual has symptoms that do not fit under ASD criteria. Some common specific comorbid diagnoses include Attention Deficit Hyperactivity Disorder (ADHD), anxiety, depression, intellectual impairment, and structural language disorders (APA, 2013).

Some symptoms of ADHD and ASD, such as extreme focus, impulsivity, and hyperactivity overlap. These overlaps can result in a mistaken diagnosis for ADHD in solidarity (Szalavitz, 2016). Other typical symptoms of ASD including rigidity, hyperfocus, and aversion to change are also common in Obsessive Compulsive Disorder, so those with ASD may also be hidden within this population (Szalavitz, 2016). Around 70% of individuals with ASD have a comorbid mental disorder and 40% may have two or more accompanying mental conditions (APA, 2013). Mental health conditions should only be diagnosed separate from ASD if the level of anxiety or depression has a significant impact on the individual's level of functioning and is not better explained by the diagnosis of ASD. Difficulty determining comorbid disorders during assessments has been associated with vague referral questions, difficulty obtaining accurate case histories, poor client cooperation, and the lack of adolescent and adult testing measures (Trammell, 2013).

**Intellectual Disabilities.** Among individuals with ASD, the most prevalent comorbid condition is an intellectual disability (Trammell et al. 2013). In 2003, an in-depth study of autism and pervasive developmental disorders found that an average of 70% of individuals with ASD also have an intellectual disability (Fombonne, 2003). When diagnosing young children, ASD and intellectual disabilities may look similar, especially if the child is so young that they have not developed language skills. It is not necessary to separately diagnose intellectual disabilities in those with ASD unless the individual's communication skills are ill-proportionate to their developmental level. It is possible for these two conditions to co-occur, but it is not always the case. The main distinction between intellectual disabilities and ASD is the presence or lack of restrictive, repetitive behaviors (APA, 2013). If girls have a lower IQ range, it may be that they are diagnosed with an intellectual disability, but if their IQ is average, healthcare professionals may assume the diagnosis is not ASD, even though the two are not mutually exclusive (Cridland et al., 2013).

### **Males vs. Females**

The ratio of males to females with diagnosed ASD is 4:1 (APA, 2013). The disparity is believed to exist for a variety of reasons such as the lack of external behaviors, alleged camouflaging techniques, and differing restrictive, repetitive behaviors. These are loopholes through which researchers believe females are being under-diagnosed (Bargiela et al., 2016; Harrop et al., 2015). Allison Shefcyk, a research assistant at the University of Connecticut's Center for Excellence in Developmental Disabilities said, "To be a female with an ASD is to be twice excluded: one from the neurotypical female population, and once again from the ASD community" (Shefcyk, 2015, p. 132). Ami Klin, director of the Marcus Autism Center at Emory

University School of Medicine describes the disparity by saying, “Females are the orphans of the autism world” (Volkers, 2018, p.48).

### ***Masking***

Research on typically developing children has shown that there is a developmental advantage in play and social communication in girls in comparison to boys (Harrop, 2015). These skills result in a camouflaging ability, which is, perhaps, one of the main reasons girls with ASD are not being diagnosed. Volkers (2018) states that females are typically more socially motivated than males, which can be seen in their hobbies, interactions, and lifestyles. With intense pressure from society for females to behave according to the societal construct of the female gender, the expectations for these girls are enforced early (Volkers, 2018; Ratto et al., 2018). Societal pressure can stem from bullying from peers or reprimands from teachers or authoritative adults. In trying to fit in with peers, females are suppressing the characteristic symptoms of ASD and hiding their disability, thus interfering with the detection of ASD. Often in childhood, young girls with ASD find a female they deem “successful” and mimic her appearance and behavior in hopes to be accepted. In observing others’ interactions, females with communication impairments memorize scripts and social behaviors to help them blend into society (Volkers, 2018).

When looking at parental-reported core cognitive skills, it was found that what parents reported varied from what was found in diagnostic measures in regard to adaptive behaviors and daily social functioning. Such discrepancies can be seen as a result of female masking and a probable cause for less females receiving a diagnosis (Ratto et al., 2018). When asked about the differences in their child’s behaviors in and out of the home, parents of females described that

their girls made a conscious effort to blend in and hide difficulties when in public (Sutherland et al., 2017).

A study completed by Dean, Harwood, and Kasari (2016) took place on a playground and examined how the social construct of gender helped females mask their symptoms. Three types of engagement states were noted during the observation: game, joint engagement, and solitary. The researchers found that males with ASD spent most of their time in solitary while their typically-developing male peers engaged in game. Due to the contrasts of these two states, there was apparent social isolation of these males. Females on the other hand, spent more time in joint engagement, which was true for those with and without ASD. However, typically developing females were readily accepted into peer activities while those with ASD used compensatory behaviors to gain access into said activities. There was apparent difficulty maintaining mutual involvement in social groups, thus these females were seen going from group to group. Because of the fluidity of female groups, those with ASD were concealed by hovering while the typically developing females remained in a single interaction. Even though they were in close proximity to others and had ample opportunities for interaction, they did not have the necessary skills to successfully engage, thus they weaved in and out of activities. The findings of Dean et al. (2016) suggest gender constructs inadvertently shape the way ASD behaviors are tolerated and perceived. When females are in joint engagement, more mature communication skills are needed than when males are playing a game. In analyzing their study, researchers found that when looking at rejection and acceptance of the ASD population, males were blatantly rejected while females were not accepted nor rejected, just overlooked and ignored (Dean et al., 2016).

While young girls are seen to struggle with the widely accepted female social construct, it only becomes more difficult with adolescence. Adolescent females engage in more complex

social interactions that include reciprocated sharing, offering of emotional support, and indirect passivity. Once conversations have developed to this extent, the once “strong” skills of imitation, pretend play, and focus are no longer effective camouflage (Cridland et al., 2013). In an interview by Bargiela, Steward, and Mandy (2016), adult females with ASD described their feelings on being overlooked and misunderstood. One participant described the consequences for pretending to be and being perceived as normal was to go unnoticed while another explained that she felt that it was imperative for her to satisfy others and express remorse when she did not fit into society’s expectations (Bargiela et al., 2016).

### ***Different Restrictive Repetitive Behaviors***

Although some studies have found that females exhibit fewer restrictive, repetitive behaviors, many others have found similar proportions of these behaviors, but within differing realms of interests (Volkers, 2018; Sutherland et al., 2017; Harrop et al., 2015). While characteristic restrictive, repetitive behaviors may not fit within male gender norms; those of females exist within appropriate female interests such as dolls, horses, and princesses (Volkers, 2018). The types of interests and behaviors may be typical, but the intensity and manners around the behaviors are not. A lack of imagination and creative story lines are presented as dolls and figures say and do the same things each time the child plays (Volkers, 2018). Static visual scenes and scripts are set up when playing with seemingly typical toys and items. It may appear that females are engaging in typical play, but they may actually be sorting their toys by size or color and arranging them in various ways (Szalavitz, 2016). Because these interests and play scenarios for females are considered more appropriate, the play of a female may not be viewed as repetitive or restrictive behaviors as described in the criteria for an ASD diagnosis thus serving as interference with the diagnosis of the population (Harrop et al., 2015).

### *Sex-Based Theories*

There are two main sex-linked theories as to why the disparity between females and males with autism spectrum disorder exists. First suggested in 1944 by Hans Asperger and later re-examined in 1997 by Simon Baron-Cohen, the extreme male brain theory expands on the Empathizing-Systemizing Theory that discusses how females are more likely to empathize with others whereas males are more likely to systemize and analyze others (Baron-Cohen, 2002). Baron-Cohen (2011) suggests that ASD is an extreme expression of the male brain which would explain why males are more often diagnosed while females must have more extreme symptoms to be noticed.

One supporting factor of extreme male brain theory is that on average, infant males have larger brains than their female counterparts. Children with ASD have even larger brains and amygdala, resulting in an opinion that ASD could be an extreme version of the male brain (Baron-Cohen et al., 2011). The core explanation for this belief is the effect of fetal testosterone. Exposure to the hormone produces sex differences in many areas of life, including behavior and cognition. Males experience surges in testosterone once during gestation, again soon after birth, and for a third time at the onset of puberty. It is believed that the first surge affects brain masculinization. Research on amniotic fluid testosterone has shown inverse links to frequency of eye contact, extent of vocabulary, quality of social interactions, and empathy within the first five years of life (Baron-Cohen et al., 2011). Amounts of amniotic testosterone also had positive correlation with narrow interests, systemizing, and detail attentiveness. These behavioral concerns show sexual differences which suggest the possibility of fetal testosterone being a factor in the development of ASD. Another study found results that these testosterone levels also

correlated to the number of autistic traits children exhibited throughout childhood (Baron-Cohen et al., 2011).

The other sex-linked hypothesis is the female protective effect, which suggests that females have a higher genetic threshold for ASD (Robinson et al., 2015). Opinions that the female sex protects women and girls from autistic impairments is based on studies that have shown the rare genetic flaws found in females diagnosed with ASD are larger and are more damaging to functionality than those found in diagnosed males (Robinson et al., 2015). Robinson's study of twins looked to see whether more hereditary factors are necessary for females to score equivalent to males with ASD. Across her two population samples, the results showed that a greater load of familial etiology may be causal for females to receive such a diagnosis. Further research of an alleged protective component of the ASD female phenotype could aid in understanding ASD and how it can be prevented (Robinson et al., 2013). In an effort to see if the female protective component was present in a single genetic location across females, Gockley et al. (2015) tested populations of females with and without ASD to analyze three tiers of chromosome X. When trying to locate a potential protectant, no particular locale was found (Gockley et al., 2015).

### **Impacts of Not Receiving Appropriate Diagnosis**

There are many possible outcomes when a female is either misdiagnosed or goes without a diagnosis of Autism Spectrum Disorder. One of these includes a struggle to create their own identity (Bargiela et al., 2016). If their behaviors and tendencies are not accepted by others, these women do not know how to develop their own life. Undiagnosed females are often so focused on imitating others that they are not sure who they should be. Society's construct of women

being caregivers and nurturers results in the portrayal of these characteristics to fit in when in fact they are not being themselves (Bargiela et al., 2016).

Developing and maintaining friendships can also be difficult for females who are undiagnosed. While a lack of friends may not be a big deal for those who are not interested in socialization, those who do want interaction may fret over their isolation (Szalavitz, 2016). As women grow older, their interactions become more complex and passive. It can be hard for females with ASD to understand commonly found gossip, competition, and relational aggression amongst other women (Cridland et al., 2013). These sophisticated abilities are not always present in individuals with a diagnosis of ASD due to pragmatic deficits. In an interview with adult females with ASD, many said that friendships with males were more comfortable since society seems to allow them to be straightforward (Bargiela et al., 2016). In addition to friendships with the opposite sex, it was also noted that females with ASD found friendships were easier to develop online since there were not time restrictions that are present in face-to-face conversations. With equal opportunities for both parties to type a message, there is no worry about interpreting body language, nonverbal cues, and pragmatics. As a result of a more suitable environment, emotions are easier to express and in turn, support from friends is easier to access (Bargiela et al., 2016). Without a diagnosis of autism spectrum disorder, females cannot identify with the autism community and be surrounded by the support of individuals with similar life experiences. Denying females the opportunity to feel included in this group further results in a lack of individual identity and friendships (Bargiela et al., 2016).

Females without a proper diagnosis of ASD who do not receive related treatment may also struggle with exhaustion and temperamental outbursts once they arrive at home (Bargiela et al., 2016; Volkers, 2018). Consciously processing and mimicking behaviors may be an effective

temporary coping mechanism, but the effort it requires is more than most individuals can bear for long periods of time (Bargiela et al., 2016). After working hard to mask their symptoms and blend into society, they are able to be themselves at home, resulting in bouts of emotion.

Recovery time is warranted and can be spent in various ways. Females may come home from school and sleep for two hours, cry for no apparent reason, or have tantrums (Volkers, 2018).

Another difficulty that females with ASD face is vulnerability. Without a diagnosis and proper intervention, women with ASD are more likely to mistake sexual grooming for friendly attention (Cridland et al., 2013, Bargiela et al., 2016). When interacting with others, deficits in pragmatic skills and understanding of communication boundaries result in potential sexual exploitation and abuse. In a parent survey by Mademtzi, Singh, Shic, and Koenig (2018) some parents expressed that their daughters with ASD did not understand menstruation, puberty, and sex. Further worries were that their daughters may want to engage in sexual activity, but not fully understand the consequences that may arise (Mademtzi et al., 2018). When females are not given a diagnosis, caregivers may not see these issues as concerns and intervene, when in fact, they are prevalent concerns. Without imperative sexual education and pragmatic training, these females without diagnosis may even be unknowingly assaulted (Bargiela et al., 2016).

In more severe cases, misdiagnosed and undiagnosed females may be prescribed inappropriate medication or institutionalized. When mental health disorders are comorbid, self-harming or even suicide attempts may occur (Volkers, 2018). While each of these scenarios may occur in females with a diagnosis of ASD, those without a diagnosis will be affected even greater due to lack of intervention and treatment (Bargiela et al., 2016).

## **Implications of Diagnosis and Treatment**

Receiving a diagnosis of ASD can impact several domains of an individual's life as well as that of their family (Bargiela et al., 2016; Volkens, 2018). While an official label may have a negative connotation related to risks such as stress and stigmatization, the beneficial social, emotional, and psychological functions of a diagnosis are believed by physicians to outweigh the cons (Jacobs et al., 2018). A survey compiled by Jacobs et al. (2018) was completed by 16 physicians who have experience with diagnosing individuals with ASD. Results indicated that there are various psychological functions of a formal diagnosis, all of which are positive.

One function is to provide an explanation for the child's behavior. When given a medical reasoning for their child's condition, parents may feel a sense of relief as they no longer feel the need to make excuses or try and justify their child to themselves or others. Additionally, with an explanation for the individual's behaviors, others are less likely to be as judgmental towards the individual (Bargiela et al., 2016; Jacobs et al., 2018). Consequently, the feeling of blame can be lifted from the parents and the child once it is known that neither party did anything to cause the child's behaviors or deficits. A diagnosis can also serve as a confirmation that concerns were legitimate and that the many doctor's visits were worthwhile, especially when proper post-diagnostic support is offered. Ultimately, once a formal diagnosis is made, an individual's needs are more quickly recognized resulting in access to services and necessary help from caregivers, teachers, and health professionals (Jacobs et al., 2018; Madwemtzi et al., 2018; Volkens, 2018).

With a diagnosis, the individual also gains a sense of identity through better understanding themselves, which results in less self-criticism. In an interview conducted by Volkens (2018), a female who was diagnosed with ASD at the age of 35 stated that her life would have been different if she had received her diagnosis earlier in life. She believed that an earlier

diagnosis would have resulted in the vanquishing of her self-doubt, anxiety, and insecurities while also helping her to better perceive the world. When discussing the services she thought would be beneficial, the participants expressed that receptive language skills should be targeted before working on social abilities, stating that if there is a misunderstanding in comprehension, there will be a misunderstanding when trying to comprehend the expressed implications of social skills (Volkers, 2018).

### ***Early Intervention***

Intervention for individuals with ASD should begin as soon as a diagnosis is obtained in order to be most effective (Steiner et al., 2012). Early intervention includes various types of therapy to facilitate development (CDC, 2020a). Intensive and comprehensive individualized programs are found to promote development in young children and optimize communicative outcomes (CDC, 2020a; Steiner et al., 2012). Between birth and 36 months, the brain develops rapidly. Early development is important because the brain is being shaped by the environment and narrowing its potential to learn things outside of one's environment. Selective elimination is the term used to explain the pruning of neural connections at an early age (Bleile, 2015). With early intervention, the still malleable brain is able to learn skills at an easier rate than after this important developmental time (CDC, 2020a). Under *IDEA*, children under the age of three are eligible to receive services if they are at risk for developmental delays. The domains and practitioners of treatment vary from state to state (IDEA, 2004). Upon a child's third birthday, they are no longer eligible to receive early intervention services from the state. In the state of Kentucky, once a child turns three years old, they may qualify to attend preschool education programs if they have been diagnosed with a disability or developmental delay (Kentucky Department of Education, 2020).

## **Role of a Speech-Language Pathologist**

When any disorder has a component of communication deficits, such as ASD, services targeting increased language skills and success is critical. In order to receive such services, proper evaluations must first occur (ASHA, 2020a). A speech-language pathologist should be consulted when an individual suspected of having ASD is assessed, as they are an important contributor to the interdisciplinary diagnostic team with professional knowledge of communication. Formal and informal measures should be used by a speech-language pathologist to evaluate expressive and receptive language as well as pragmatic language. To complete a comprehensive assessment, speech, alternative and augmentative communication, and swallowing may also be assessed to determine further functional impacts the disorder's characteristics may have on the individual. While other disciplines may be involved in the diagnostic process, it is ultimately a speech-language pathologist that provides the secondary diagnosis of a language disorder (ASHA, 2020a).

Once an evaluation has been completed, the American Speech-Language-Hearing Association states that there are many areas in which a speech-language pathologist can provide treatment for an individual with ASD (2020a). A speech-language pathologist can implement intervention in pragmatic social skills to better prepare an individual to interact and communicate with others. The understanding and usage of words, known as expressive and receptive language, are other aspects a speech-language pathologist can target to help the individual communicate their wants and needs. Once an individual is old enough to read and write, speech-language pathologists can incorporate literacy training to improve semantic and syntactic deficits. If needed, alternative and augmentative communication devices may be incorporated by a speech-language pathologist into an individual's life if they are nonverbal and need more appropriate

means to communicate (ASHA, 2020a). With all of the aforementioned implications, the role of a speech-language pathologist in evaluating and treating an individual with ASD is paramount.

## **Chapter 3: Methods**

### **Research Design**

This was a non-experimental, retrospective case-study designed to analyze the diagnostic path of a single individual. No variables were manipulated in the study, but qualitative data was collected to explore the participant's diagnostic route.

### **Participant**

The participant in this study was a four-year-old female who received language therapy at the Murray State University Speech and Hearing Clinic. She had been evaluated previously for ASD and speech and language disorders. At the time of the study, the participant had received diagnoses of developmental delay, which includes the domains of communication and cognition, and language disorder. She had not received a diagnosis of ASD. As of November 25, 2019, she qualified for services in a public Kentucky preschool and began attending that school four days a week. She received language services from the school speech-language pathologist and special education services from the preschool teacher in the preschool setting. Additionally, she received outpatient therapy services focused on increased communication skills once a week at Murray State University Speech and Hearing Clinic.

### **Research Questions**

Answers to the following questions were sought in order to obtain more information about diagnostic procedures and the journey a family may go on in attempts to access appropriate services for their child.

1. What systemic procedures, if any, were effective in identifying the participant as being at-risk for autism spectrum disorder or developmental delay including communication concerns?

2. What role did the caregivers have in the diagnostic process?
3. What role did the caregivers have in obtaining therapeutic services?
4. Is the participant currently receiving supports necessary to be successful in improving communication skills across settings?

## **Procedures**

### ***Informed Consent***

Upon receiving permission from the Institutional Review Board and obtaining informed consent from the participant's caregivers to conduct the study, data collection began. An in-depth client history was obtained from the participant's caregiver via telephone and previous records and reports from pediatricians, early intervention providers, psychologists, teachers, and speech-language pathologists were collected. The information obtained was then aggregated into a descriptive narrative retelling the diagnostic steps taken by the participant and her caregivers. Results were carefully analyzed to report findings, answer the identified research questions, and provide conclusions and discussions about the participant's journey to seek diagnostic and therapeutic services.

### **Data Collection and Analysis**

#### ***Data Collection***

An addressed and stamped envelope was mailed to the participant's home. Her caregivers were asked to enclose copies of relevant medical and educational evaluations and reports and mail them to the researchers at the Murray State University Speech and Hearing Clinic. A phone interview was conducted with the participant's mother to obtain any additional information relevant to her daughter's diagnostic journey.

***Data Analysis***

Once data was collected, the participant's medical and diagnostic history was organized chronologically before being compared to the recommendations of medical professionals. Data analysis included the examination of individual steps that were completed throughout her childhood and their efficacy and efficiency in providing her with appropriate services.

***Data Storage***

All physical reports, evaluations, and information related to the participant collected during the study were placed in a confidential file and locked in a filing cabinet located in Alexander Hall room 111. Information obtained from telephone correspondence was transcribed and digitally compiled into a folder on an encrypted flash drive, which was also stored in the locked filing cabinet. Only the student investigator and supervisor had access to the data. On the date specified to the Institutional Review Board, all physical data will be shredded before being properly disposed of and electronic files will be permanently deleted from the encrypted drive.

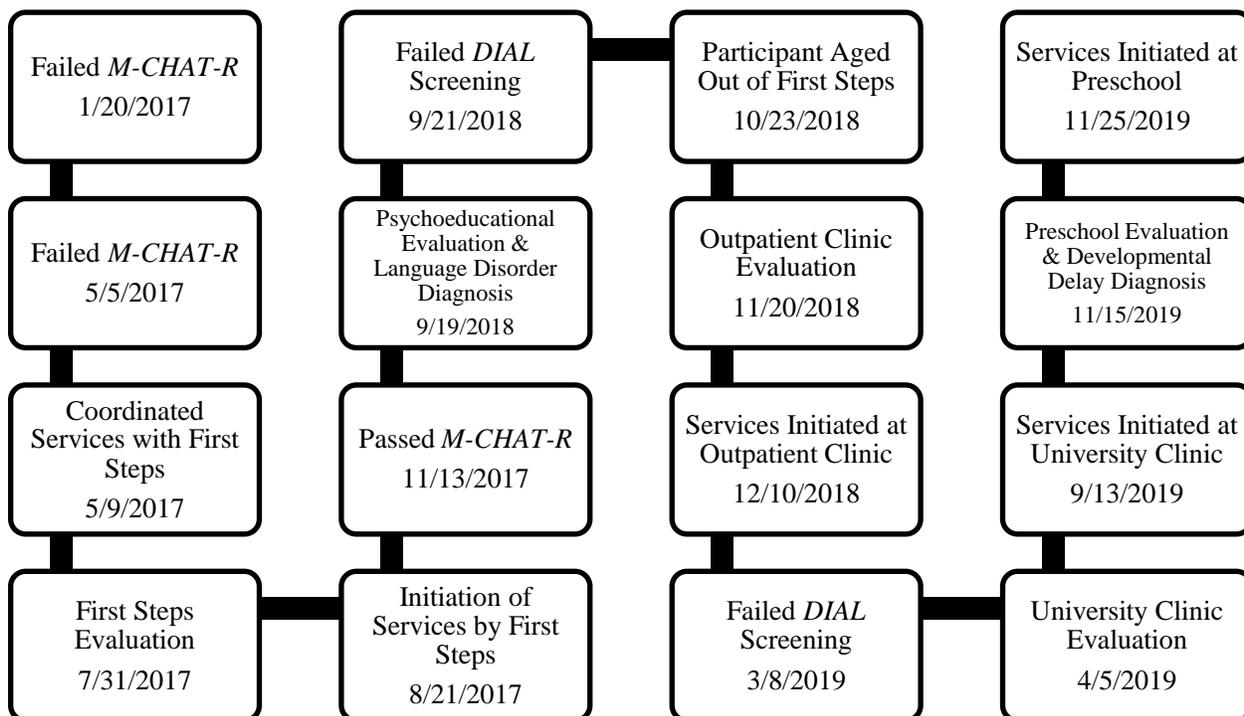
## Chapter 4: Results

This section provides a detailed description of the participant's diagnostic journey.

Information from educational and medical reports have been compiled to create a chronological sequence outlining the steps that the preschool-aged participant and family have taken to get their daughter the services she is currently receiving. The background of the case will be described including the referrals the participant has received, the results of any evaluations she has been given, and her parents' role throughout the process. Figure 1 sequences the significant events that occurred along this journey.

**Figure 1**

*Timeline of the Participant's Diagnostic Journey*



## **Case Background**

### ***Participant Description***

The participant for this study was a four-year-old female with diagnoses of developmental delay and language delay. The participant resides with her father and mother and is the only child, grandchild, and niece within her extended family. The participant currently attends a local preschool four days a week. According to the parent interview and case history forms, the participant enjoys swimming, playing outside, dancing, and engaging in pretend play. It was also noted that her least favorite activity includes group settings as she prefers to play alone. The participant's strengths were noted by her mother as being her ability to work independently and having good motor skills.

### ***Participant Case History***

**Pregnancy and birth.** The participant's mother reported receiving prenatal care throughout her pregnancy and noted that there were a few concerns, such as excessive vomiting and dehydration. The participant was delivered late term at 41 weeks gestation and weighed 8 pounds, 8 ounces. There were no noted complications during delivery. Following her birth, the participant was formula fed and weaned at nine months, ate solid foods such as cereal between four and five months, and other foods at six months.

**Medical history.** Information from the parent interview and case documents revealed that the participant is generally healthy with no hospitalizations or significant illnesses. There are no medications or allergies in the participant's medical history. While there had been no significant swallowing or feeding concerns with the participant, her mother reports that she has always been a picky eater.

**Family information.** The participant's mother is a hairstylist with professional certifications, while her father is a production manager who reported having attended college. Collected case histories indicated that the participant's father had an articulation disorder and received speech therapy as a child.

## **Developmental Milestones**

### ***The First Year***

In the participant's first year of life, she was generally healthy with an unremarkable medical history. Reports from her pediatrician indicate that at 2.5 weeks old, she was turning to sounds and focusing on faces. By two months, she was cooing and smiling responsively. At her four-month well child visit, it was noted that she was turning to voices, laughing, and squealing. The participant had been crawling for three weeks by her six-month appointment and the report also noted that she was babbling with consonants and working for toys. Three months later at her nine-month visit, it was reported that the participant vocalized "dada" and "mama" non-specifically. Regarding her social skills, the participant was not waving bye-bye and demonstrated anxiety around strangers. Physically, she was walking independently, and her growth and development were on track with same-aged peers. At this visit, it was noted that she pointed to indicate wants and that she only expressed two words: "mama" and "dada". Upon her first birthday, her pediatrician advised that her parents try to implement baby signs with the participant and recommended the book, "More than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder" by Fern Sussman.

### *First Concerns*

It was around her first birthday when the participant's parents became concerned about potential communication issues. In the parent interview, her mother noted, "She did very little mumbling and jabber, but didn't have any real words." The mother also discussed having a lot of exposure to children because of her babysitting experiences. Her background with typically developing children in addition to her friends also having same-aged children resulted in the participant's mother comparing her child to others. She reported it being a very scary time at the beginning of their journey as she had never been around kids with any type of delay and was unsure of what to do since society rarely talks about delays. Additionally, she expressed the intense nature of her fear since it was her own child who was experiencing these delays.

At the participant's 15-month well-child visit, her pediatrician administered the *Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)*. Despite the incorporation of follow-up questions, responses provided by the participant's parents indicated a failed screening. In response to these results, the pediatrician made a referral for a hearing evaluation at the Murray State University Speech and Hearing Clinic, a speech therapy evaluation with First Steps, and a CEC evaluation at Vanderbilt Children's Hospital in Nashville, TN. The ICD-10 codes used for this visit were F80.9 indicating a developmental disorder of speech and language, unspecified and R62.50 denoting an unspecified lack of expected normal physiological development in childhood. Aside from these concerns, her medical records indicated typical growth regarding height, weight, and physical development.

At her 18-month appointment, the *M-CHAT-R* was readministered. Although her parents had changed some of their answers since the previous visit, the checklist continued to provide a failed score. In this appointment's report, it was also noted that the participant did not point to

body parts and only knew 3 or 4 words. At this time, the participant's family had not sought out any of the previously recommended services. Once more, referrals for hearing, speech therapy, and CEC evaluations were made.

### **Hearing Evaluations**

In order to rule out hearing loss as a contributing factor related to delayed speech development, the participant underwent several hearing screenings. The patient's mother indicated no history of ear infections, family hearing loss, or significant noise exposure. Her mother also reported that she passed her newborn hearing evaluation in both ears. At 19 months, the participant went to the Murray State University Speech and Hearing Clinic to have a hearing evaluation completed by an audiologist as referred by First Steps. Based on the report from the audiologist, the participant would not allow the probe tip to be placed in her ears and protested when her mother tried to hold her still during the process. Visual reinforcement audiometry in the sound field of the audio booth suggested a presence of hearing loss, but the reliability was only fair due to participant compliance. The audiologist noted that the participant did not localize to tones or speech, and further testing was recommended to improve reliability of the participant's responses. One month later, she was seen for another hearing evaluation. Visual reinforcement audiometry in the sound field of the audio booth yielded a speech awareness response at 10dB and minimal responses to narrow band noise and warbled pure tones from 10-15dB. Tympanometry nor otoacoustic emissions were obtainable due to opposition to having her ears touched. Results from the appointment were inconclusive for describing overall hearing sensitivity due to testing difficulties, but the audiologist believed her hearing to be adequate for developing speech and language.

When the participant was three-years-and-six-months old, graduate clinicians at the Murray State University Speech and Hearing Clinic attempted to complete a hearing screening; however, it was unable to be completed due to an unconditioned participant and a lack of compliance with the headphones. However, ten days later, the school speech-language pathologist was able to administer a hearing screening and the participant passed at 25dB. Despite inconsistent compliance and results, it was believed that the participant's hearing was not impacting her communication development.

### **Kentucky First Steps**

Four days after failing a second *M-CHAT-R* administered by her pediatrician and receiving a referral for early intervention services, the participant's caregivers coordinated initial services with Kentucky First Steps and scheduled an evaluation. Nearly three months later, the participant was evaluated by First Steps in her home using both formal and informal measures. At the time of the assessment, the participant was 21 months old. The five developmental domains assessed during this primary level evaluation were motor, communication, cognitive, self-help, and social/emotional. The assessment included a behavioral observation and the administration of the *Carolina Curriculum for Infants and Toddlers with Special Needs, Third Edition (CCITSN)* and the *Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III)*. During the evaluation, the evaluator noted that the participant was interested in the testing materials, but was not always cooperative.

Results of the criterion-referenced *CCITSN*, located in Table 1, revealed that the participant's communication was significantly below average for her age in the areas of both receptive and expressive language. This assessment also indicated that her self-help and social-emotional skills were slightly below those of children her age.

**Table 1***CCITSN Results*

<b>Domain</b>	<b>Age Equivalent</b>	<b>Description</b>
Gross Motor	25-26 months	Slightly Above
Fine Motor	17-18 months	Slightly Below
Receptive Language	10-14 months	Significantly Below
Expressive Language	12-13 months	Significantly Below
Cognitive	18-19 months	Within Typical Range
Self-Help	17-18 months	Slightly Below
Social/Emotional	17-18 months	Slightly Below

Scores from the *Bayley-III*, found in Table 2, yielded similar results, indicating significantly below average language performance, slightly below average self-help and social/emotional skills, and average cognitive and motor abilities. The norm-referenced assessment provided standard deviations from same-aged peers amongst all developmental domains.

Consistent across both standardized measures, the participant's communication skills warranted the most concern with her receptive language scores being slightly lower than those of expressive language. In regard to the participant's receptive abilities, the evaluator noted that while the participant would turn to find noisy toys outside of her visual field, she rarely turned whenever her name was being called. She would interact with toys for at least one minute, but did not sustain attention for as long when engaging with the evaluator. Her mother reported consistently clear responses to the words "bye" and "Mickey," and she demonstrated that she could wave bye on request. Evaluation notes reported the participant's inability to identify

common objects or pictures and follow one-step directions when given a baby or bear. She also neglected to respond to inhibitory words such as “no,” “wait,” “stop,” or “not yet,” without physically being made to stop.

**Table 2**

*Bayley-III Results*

<b>Domain</b>	<b>Composite Score</b>	<b>Description</b>	<b>Age Equivalent</b>	<b>Standard Deviations</b>
<b>Motor</b>	<b>97</b>	<b>Average</b>		<b>-0.20</b>
Gross Motor			25-26 months	
Fine Motor			17-18 months	
<b>Language</b>	<b>65</b>	<b>Significantly Below Average</b>		<b>-2.33</b>
Expressive			12-13 months	
Receptive			10-11 months	
<b>Cognitive</b>	<b>90</b>	<b>Average</b>		<b>-0.67</b>
<b>Self-Help</b>	<b>84</b>	<b>Slightly Below Average</b>		<b>-1.07</b>
<b>Social/Emotional</b>	<b>80</b>	<b>Slightly Below Average</b>		<b>-1.33</b>

While assessing her expressive skills, the evaluator indicated that the participant jabbered with inflection, elicited the spontaneous production of “What is it?,” “I don’t know,” and “bye,” and counted through the use of an inflected “eh”. When asked if she wanted a bite, the participant shook her head no, but her mother reported that she shakes her head to everything, even when she means “yes” rather than “no”. Her mother also indicated that the participant could

say “bite,” “momma,” “dadda,” “yeah,” and a name for her grandmother. Although she was able to say “bite,” she only would do so when she was looking at food, suggesting the possible function of labeling. The evaluator noted that the participant was unable to name common objects or pictures and did not attempt to imitate sounds, syllables, or words when requested. During the evaluation, the participant communicated some through gestures, but did not produce very many words. Secondary to the behaviors above, her mother reported that she easily gets very frustrated when unable to communicate her wants.

Evaluation outcomes indicated that the participant had a strength of gross motor abilities and weakness in the areas of communication. It was also noted that her delayed communication could have been negatively impacting her social-emotional and self-help areas. Due to these concerns, the participant began receiving speech therapy from First Steps one month after her evaluation. The participant’s mother indicated that the first speech-language pathologist they were assigned was not a good match for their family. Issues such as forgotten appointments and scheduling conflicts were very common. However, when assigned a different speech-language pathologist, the mother reported being very pleased. No problems ever arose, and the mother appreciated that she was given activities to work on outside of therapy to better facilitate the participant’s communication. The participant continued to receive services from First Steps until her third birthday.

### **24-Month Well-Child Visit**

A few weeks after the participant’s second birthday, she and her mother attended her 24-month well-child appointment with her pediatrician. Her medical chart indicates a passing score on the *M-CHAT-R* during this appointment. This was her first passing score as the two prior screenings were failed. The pediatrician noted normal growth and development aside from her

delayed speech. Since beginning speech therapy a few months prior, her mother expressed that she had not observed much improvement and requested a second opinion from another therapy facility. Notes about the participant's language indicate that she had an expressive lexicon of less than 10 words at this time and did not combine words. Additionally, it was documented that she did not verbalize her wants and often became frustrated when her mother did not know what she wanted or needed. Tantrum occurrences were also mentioned in the appointment report regarding her behavior. The pediatrician counseled the mother on language development, highlighting the importance of modeling appropriate language, daily reading, and listening to her child's response and then responding. When handling her temperament and behavior, the pediatrician recommended praising the participant for good behavior, teaching her to respect others, and helping her express her feelings. At this age, he also mentioned that she should have a desire to play with other children, which contradicted the participant's behaviors.

### **Psychoeducational Evaluation**

The next appointment for the participant's family was with a psychologist at a university assessment center when she was two-years-and-ten-months old. The evaluation report indicated that the reasons for the evaluation were her parents' concerns related to their daughter's communication and social skills. In a semi-structured interview, the psychologist gathered information relevant to the participant's developmental history before completing a behavioral observation and administering the *Bayley Scales of Infant and Toddler Development - Third Edition (Bayley-III)* and the *Vineland Adaptive Behavior Scales - Third Edition (Vineland-3)* to assess global developmental functioning and the *Behavior Assessment System for Children - Third Edition (BASC-3)*, which looks at psychosocial functioning.

Pertinent background information from the evaluation report indicated that the participant's parents first noticed her dislike of public settings when she was one year old. She reached developmental milestones later than expected and at 18-months, she was enrolled in speech therapy with Kentucky First Steps. When discussing the participant's behaviors at home, her parents stated that the child was hyperactive, had a poor attention span, and threw temper tantrums when she did not get her way. At school (Mother's Day Out), she had difficulty sharing and waiting her turn, but the parents reported no other issues. During the behavior observation, the evaluator noted that the participant was easily distracted by the toys in the room and became less cooperative with him when this happened.

When comparing the previously administered *Bayley-III* results as reported by Kentucky First Steps to the second administration by the psychologist, similar, but not exact scores are obtained. Kentucky First Steps assessed all five areas of development, while the psychologist only assessed those of concern - cognitive and language as reported in Table 3. The participant's language composite score increased from 65 to 68, remaining significantly below average, while her cognitive composite rose from 90 to 95, remaining in the average range of functioning, misaligning with her parents' rating of her intelligence as below average. In the cognitive domain, she was able to group objects by color, compare masses, and count to 10. She exhibited difficulty when prompted to match cards, identify out of place objects, and identify incomplete images. After assessing receptive language, her abilities were classified as borderline functioning while her expressive skills were labeled as being low average.

**Table 3***Bayley-III Results*

<b>Domain / Subdomain</b>	<b>Scaled Score</b>	<b>Composite Score (90% Confidence Interval)</b>	<b>Percentile Rank (%)</b>	<b>Descriptive Classification</b>
<b>Cognitive</b>	<b>9</b>	<b>95 (89-102)</b>	<b>37</b>	<b>Low Average</b>
<b>Language</b>	<b>9</b>	<b>68 (64-76)</b>	<b>2</b>	<b>Low Average</b>
Expressive	9	-	-	Low Average
Receptive	5	-	-	Borderline

The *Vineland Adaptive Behavior Scale, Third Edition (Vineland-3)* assesses adaptive behavior in the domains of communication, daily living skills, and socialization. Also within the assessment are optional areas of motor skills and maladaptive behavior. The assessment was completed as an interview and rating form with the participant's mother. Table 4 indicates that the participant was placed in the moderately low range for communication, daily living skills, and socialization domains by her mother. Consistent with information collected through the parent interview, the *Vineland-3* suggested that the participant has difficulty expressing herself to others.

The *Behavior Assessment System for Children - Third Edition (BASC-3)* is a comprehensive, norm-referenced measure of behavioral, social, and independent functioning. Results from the Parent Rating Scales in Table 5 indicate some concern regarding her disruptive or uncontrolled behaviors, which her mother corroborated by stating that she is overly active and often has poor self-control. Regarding adaptive skills, the participant's mother reported that her daughter often prefers to play alone, interrupts others, and speaks in short phrases that are difficult to understand. However, she reported that overall, she was well-adjusted and coped well

with her everyday environment. While there were some at-risk areas, the psychologist reported that the results were not significant enough to warrant follow-up.

**Table 4**

*Vineland-3 Results*

<b>Adaptive Skill Area</b>	<b>Standard Scores (90% Confidence Interval)</b>	<b>Age Equivalent / Percentile Rank</b>	<b>Adaptive Level</b>
<b>Communication</b>	<b>78 (74-82)</b>	<b>7th Percentile</b>	<b>Moderately Low</b>
Receptive	12	2 years 0 months	Moderately Low
Expressive	9	1 year 7 months	Low
<b>Daily Living Skills</b>	<b>80 (75-85)</b>	<b>9th Percentile</b>	<b>Moderately Low</b>
Personal	11	0 years 10 months	Moderately Low
<b>Socialization</b>	<b>75 (72-78)</b>	<b>5th Percentile</b>	<b>Moderately Low</b>
Interpersonal Relationships	9	0 years 10 months	Low
Play and Leisure	13	1 year 11 months	Average
Coping Skills	9	< 2 years	Low
<b>Adaptive Behavior</b>	<b>76 (74-78)</b>	<b>5th Percentile</b>	<b>Moderately Low</b>

The psychoeducational evaluation results indicated that the participant’s language skills, both expressive and receptive, were well-below the levels of same-aged peers. These delayed skills were reported to have a profound impact on the participant’s ability to interact with individuals in her environment. The psychologist stated that her language deficits “manifested in behavioral oddities and problematic behaviors.” The dynamic assessment resulted in the diagnostic label of Language Disorder according to criteria found in the *DSM-V*.

**Table 5***BASC-3 Results*

Scale	T-Score	Percentile Rank	Descriptive Range
<b>Externalizing Problems</b>	<b>63</b>	<b>90</b>	<b>At-Risk</b>
Hyperactivity	69	95	At-Risk
Aggression	55	78	Average
<b>Internalizing Problems</b>	<b>46</b>	<b>39</b>	<b>Average</b>
Anxiety	49	55	Average
Depression	53	69	Average
Somatization	37	1	Average
<b>Adaptive Skills</b>	<b>37</b>	<b>9</b>	<b>At-Risk</b>
Attention Problems	56	73	Average
Atypicality	59	86	Average
Withdrawal	54	68	Average
Adaptability	47	39	Average
Social Skills	40	16	At-Risk
Functional Communication	37	11	At-Risk
Activities of Daily Living	34	5	At-Risk

Intensive language therapy was recommended to target both the form and function of language in order to remediate the participant's skills. It was also suggested that the participant should be reevaluated six to twelve months later to determine if therapy interventions are appropriate. The parents were encouraged to model appropriate behavior and language during

structured play as well as use prompting and extinction strategies when their daughter demonstrated noncompliance.

### **Outpatient Clinic**

Once the participant aged out of the speech services provided by First Steps when she turned three-years-old, her mother took her to a private outpatient therapy clinic located an hour away from their home to receive an evaluation due to expressive language concerns. During this evaluation, a behavior observation and parent interview were conducted. The evaluator obtained information from the participant's mother regarding her daughter's development, medical history, communication, and behaviors. Similar findings to previous evaluators were recorded.

No significant medical history was reported by the participant's mother. The evaluation occurred after she had been assessed for a potential diagnosis of ASD, but was instead determined to have a delay in her language and concepts. The participant was still attending daycare at Mother's Day Out three days a week. Her mother reported that she interacts well with peers during play, but that she demonstrates issues with sharing her toys. At this point in time, the participant was primarily communicating through a combination of gestures, such as grabbing and pointing, one-word utterances, infrequent two-word combinations, and strands of jargon. It was noted that she had approximately 60-80 words in her expressive vocabulary. Receptively, the participant exhibited an inconsistent ability to identify objects or body parts and required two-step commands to be broken down. Because of this communication profile, her parents continued to be concerned about the progression of her speech and language skills.

During the behavior observation, the speech-language pathologist reported that the participant was pleasant and curious. She shifted rapidly between tasks and only participated in structured tasks for brief moments at a time. The participant answered simple questions

intermittently when prompted and attended to her name when prompted by the evaluator and her mother. During play, she was primarily self-driven and demonstrated typical to high levels of energy. Her mother agreed that all observations during the evaluation were typical of her child's behaviors.

While there was no reported swallowing or feeding concern, it was noted that the participant preferred certain foods, but would eat a variety of food textures and consistencies. A dislike of vegetables was also indicated in the report. An informal oral mechanism examination suggested adequate muscle tone and range of motion needed for speech. Her facial structures were intact and symmetrical at rest. It was noted that a formal oral examination would be completed during therapy sessions, but there was no indication of such in the therapy notes.

A formal evaluation of the participant's articulation was not completed secondary to time constraints and reduced attention to task. Her mother reported understanding 40%-50% of what her child said while unfamiliar listeners could understand less than 30% of her speech. By the participant's age of three, she should have been 75% intelligible to all communication partners across all settings. While her speech did appear to be delayed, language was the main area of concern during the evaluation. Language development notes indicate that the participant began babbling with various speech sounds when she was four months old. From one to two years, her mother reported that she primarily communicated with jargon and produced no real words. At two years old, she began spontaneously producing words and then combined two words inconsistently six months later.

The speech-language pathologist indicated that during the evaluation, the participant produced very few functional words spontaneously, but used primarily single words. Additionally, she demonstrated an inconsistent ability to label objects when prompted. "See you

soon,” “Bye-bye,” and “Clean up” were the only elicited utterances that were longer than one word. The evaluator expressed that she should be using three to five-word utterances to express her wants and needs. The participant accurately followed one-step commands given by the evaluator, but only when provided with gestural cueing and moderate verbal prompting. When asked simple yes or no questions and wh- questions (who, what, where, when, why), the participant provided no response by neither gesture nor verbalization.

Based on parent report, observation, and informed clinical opinion, the evaluating speech-language pathologist indicated that the participant presented with a moderate total language delay that was negatively impacting her ability to communicate her wants and needs with adults and peers. The participant met the criteria for skilled intervention and had a positive prognosis due to parent involvement and her young age. Her mother agreed to participate in a home education plan and bring her child to the clinic to receive therapy services once a week for thirty minutes.

Recommended objectives for the participant’s therapy sessions included increasing her ability to request needs through words and phrases, taking communicative turns during predictable games, producing age-appropriate utterances during language probes, increasing her ability to receptively identify objects, pictures, and body parts, independently following two-step commands, and answering simple wh- and yes or no questions. Also mentioned in the report’s recommendations was parent participation in a home education program.

### ***Therapy Sessions***

During weekly sessions, the speech-language pathologist provided interventions targeting several aspects of expressive and receptive language. The participant’s therapy goals included increasing her use of functional language to help decrease frustrations, answering wh- and yes/no

questions, using age-appropriate pronouns, prepositions, and adjectives, participating in conversational turn-taking, and participating in a home education program as well as an oral motor program to increase tone and range of motion, while decreasing drooling.

Objective data from the first six sessions reported that when verbalizing, the participant primarily imitated the speech-language pathologist with word approximations and poor intelligibility. She demonstrated a lack of functional language to request needs and primarily used words as labels. Additionally, she was unable to consistently answer yes/no or wh- questions, which coincided with her mother's comment about her looking like "a deer in headlights" when asked a question. Maximum cues were often needed for the participant to remain engaged and she was easily upset when redirected or asked to do a non-preferred task.

During the latter half of the participant's appointments, therapy notes indicate that she independently requested on multiple occasions, imitated "Help, please", and spontaneously used some three-to-five-word utterances. She often imitated the therapist's utterance for conversational turns, but occasionally ignored the therapist when prompted to take turns. In the event that the therapist took turns in non-preferred ways, the participant protested "No" or "Stop". When asked a yes or no question, the participant consistently responded with either "no" or "okay", which were not always appropriately used in context. The participant was inconsistent when answering wh- across sessions with some higher accuracies and other silent responses. By the last few sessions, the therapist indicated the participant's increased use of pronouns after several sessions of auditory bombardment. Throughout the time she received services, the participant actively participated in most activities with minimal cues, but required increased cueing for more structured activities.

When asked about the family's experiences at the clinic during a parent interview, the participant's mother commented on the hour-long commute from their home to the facility. She also reported being unable to watch therapy sessions. Overall, the participant's mother indicated that her daughter enjoyed going to her weekly therapy sessions. However, after not noticing any progress being made, the family decided to discontinue services. The participant attended therapy sessions at this facility for five months and attended 14 sessions before discontinuing services. It should be noted that the participant received interventions from three different speech-language pathologists during this time.

### **36-Month Well-Child Visit**

At the participant's 36-month visit with her pediatrician, her mother indicated that she was attending Mother's Day Out three days a week and receiving speech therapy at an outpatient clinic. While there were no reported concerns with her hearing, the participant's eating habits were discussed. The pediatrician provided the family with a picky eater's handout in addition to diet and exercise education, guidance, and counseling. Anticipatory guidance was given regarding family support, literacy, and play. The participant's parents were advised to reinforce appropriate behavior, show affection, and reinforce limits when managing their child's behavior. To promote literacy, activities such as reading, singing, and talking about pictures in books were proposed. The pediatrician also recommended that her parents try and encourage her to talk more often and engage in fantasy play as well as joint play with peers.

### **University Speech and Hearing Clinic**

#### ***Evaluation***

Shortly before discontinuing therapy at the outpatient clinic, the participant had an evaluation completed at a local university speech and hearing clinic. The participant's mother

provided a copy of the previous psychoeducational report as well as the First Steps report to the supervising speech-language pathologist and graduate student clinicians. When asked about primary communication concerns, the participant's mother elaborated on her child's inability to respond to questions, engage in conversation, and attend to tasks. She also stated that unfamiliar listeners struggled to understand her speech and that she often had to repeat herself to have her wants and needs understood. Additionally, her mother reported that while she attended Mother's Day Out three days a week, she did not often engage in structured activities and struggled to follow directions independently.

During the evaluation, the client exhibited several protesting behaviors, which interfered with a hearing screening, oral mechanism examination, and formal speech evaluation. The hearing screening was unable to be completed due to the participant's lack of a conditioned response to the auditory stimulus. Additionally, she continuously pushed away the headphones. When prompting the participant to elicit oral motor movements needed for the oral mechanism examination, the clinicians and supervisor were unable to get any responses from the participant. While attempting to administer the *Goldman-Fristoe Test of Articulation 3 (GFTA-3)*, the participant repeatedly pushed away testing materials and protested, "No." Due to lack of cooperation, the clinicians and supervisor could not obtain target words necessary for scoring the assessment. Anecdotal notes were taken, indicating the participant's speech being intelligible within known context. Some developmental phonological processes were present in her speech.

To determine the participant's strengths and weaknesses in both receptive and expressive language areas, the communication domain of the *Developmental Assessment of Young Children, Second Edition (DAYC-2)* was administered. Her language abilities are described in Table 6 and reported to be "poor" in comparison to her peers. Her receptive language strengths included

identifying at least six body parts and following one-step directions. Receptive weaknesses consisted of her inability to answer wh- questions, compare objects by color or size, or point to pictures or objects. It should be noted that when asked to point to a target item, the participant refused, verbalized, “No,” and knocked the presented items out of the clinician’s hands.

Regarding expressive language, the participant’s strengths were having a lexicon of at least 50 words, using two-to-three-word phrases when given a model, and using appropriate greetings when provided with a verbal prompt. Her expressive weaknesses were asking questions, naming objects, and having appropriate prosody. The *DAYC-2* provided the participant with a total communication score described as poor.

**Table 6**

*DAYC-2 Results*

<b>Domain</b>	<b>Standard Score</b>	<b>Percentile Rank</b>	<b>Descriptive Term</b>
Receptive Language	72	3	Poor
Expressive Language	75	5	Poor
Total Communication	74	4	Poor

During a behavior observation, graduate clinicians indicated that the participant’s preferred items and activities included play-doh, cause-and-effect toys, a water sensory mat, and dressing a baby doll. While playing, the participant continuously imitated and repeated the clinicians’ statements, but produced very few spontaneous utterances. When asked if she needed help, the participant indicated so through gesture use. She was provided with a verbal model to request and later in the appointment, she imitated the model to indicate needing help. When non-preferred activities were presented, the participant protested saying, “No” or “All done”, pushed items away, and turned away from the clinicians. It was also reported that she verbalized “all

done” repeatedly and put items on the table when no longer interested in engaging with the supervisor and clinicians. Based on her case history, assessments, and behavior observation, it was recommended that the participant receive skilled interventions focused on expressive and receptive language skills in this clinical setting.

### *Therapy Sessions*

During her first year of therapy at the university clinic, the participant had one graduate clinician and one graduate supervisor present at each weekly session. Her long-term objective for both semesters was as follows “[Participant] will increase her abilities to effectively use expressive and receptive language skills.” Short-term objectives targeted correctly answering “wh” questions, using intelligible three-to-four-word utterances, following two-step directions, pointing to targeted items and actions, and understanding and use of age-appropriate prepositions.

Initially, the participant did not remain engaged in an activity for longer than five minutes, but rather moved rapidly from one task to the next. Echolalia made up the majority of the participant’s utterances as she often repeated the clinician’s utterances either immediately or after a delay. Some protesting behaviors were exhibited when presented with non-preferred items and activities throughout the semester. The provision of visual supports, such as a picture schedule and visual timer greatly reduced the prevalence of the participant’s protesting behaviors.

At first, an interactive visual schedule was incorporated so that the participant got to choose the next activity while reinforcing the idea of changing what was on the schedule. After a few sessions, a concrete visual was provided and she quickly adapted to this change, following the appropriate sequence of activities, and calling attention to the schedule upon completion of

each therapy task. It was very evident that the participant relied on these visual supports when the clinician either pulled back the supports or deviated from the schedule. Language modeling, direct teaching, and auditory bombardment were the most heavily implemented interventions in therapy sessions. Additionally, the supplementation of verbal and visual cues and prompts facilitated the participant's engagement and language usage during therapeutic activities.

After the first semester of therapy, the *DAY-C* was readministered to explore potential communication progress. Receptively, the participant demonstrated difficulty understanding negatives and prepositions. Strengths included being able to answer simple comprehension questions, understand the concept of "who", and acknowledge possessives. When assessing expressive skills, the participant was able to use regular plurals, answer simple "what" and "where" questions, and demonstrate appropriate facial expressions to depict emotions. She showed difficulty when prompted to define simple words, answer "what if" questions, and change speech when communicating with different listeners. Scores in Table 7 suggest improvement since the previous administration, but below average performance continued to be observed. Additionally, the *Descriptive Pragmatics Profile* from the *Clinical Evaluation of Language Fundamentals, Preschool, Second Edition (DAYC-2)* was completed by the participant's mother to gain additional insight into the participant's social skills outside of the therapy room. The profile indicated that the participant's nonverbal communication skills were either often or always appropriate. In the areas of conversational skills and expressive communication, the listed behaviors were only sometimes or often demonstrated. Her mother indicated that she sometimes demonstrated turn-taking skills, stayed quiet when expected, maintained attention while someone else was speaking, or asked for permission when necessary.

**Table 7***DAYC-2 Results*

<b>Domain</b>	<b>Standard Score</b>	<b>Percentile Rank</b>	<b>Descriptive Term</b>
Receptive Language	81	10	Below Average
Expressive Language	84	14	Below Average
Total Communication	82	12	Below Average

The participant made progress toward each of her language goals during the first year of therapy, but her abilities remained below those of her same-aged peers. Her performance indicated mastery of her receptive pointing goal, suggesting improvement in her vocabulary comprehension. When answering “wh” questions, the participant was noted to provide more accurate responses when provided with visual supports or a limited field. Data trends indicated her inconsistent production of utterances consisting of three or more words across the duration of therapy. Overall, improvement in her expressive and receptive skills were observed since the initiation of interventions.

**Preschool*****Screening, Intervention and Evaluation***

Qualifications for attending Kentucky preschool programs have been set forth by the Kentucky Department of Education. Preschool education programs are available to children with disabilities or developmental delays once they are three years old (Kentucky Department of Education, 2020). As noted in the evaluation report from a local preschool, the participant was initially screened at the local preschool shortly before her third birthday. This screening occurred as a routine process for First Step children who were aging out of services. The participant’s parents had previously signed a form refusing the transition to preschool in the summer. Upon a

failed screening using the *Developmental Indicators for the Assessment of Learning, Fourth Edition (DIAL-4)* at the preschool, her parents stated that they still did not want to transition her to preschool at the time of her third birthday in the month of October. During the exit interview with the parents, it was recommended that the participant return for the mass screening in the spring to rescreen areas of concern including communication and cognition.

In March 2019, the parents followed through with recommendations and called the school to inquire about rescreening. The participant was given an appointment and was screened once more at the preschool using the *DIAL-4*. At the time, the participant was nearly three-and-a-half-years-old. She passed her screening in the areas of self-help and social-emotional, but potential delays were suggested in areas of motor, communication, and cognition. At that time, the participant's parents were provided with intervention strategies and activities by an interdisciplinary early childhood education teacher to address her communication and cognition at home. Her parents did not report any concern with motor skills; therefore, interventions in this area were not provided. Intervention strategies included caregiver coaching, modeling, direct instruction, repetitions, verbal prompts, visual cues, positive reinforcement, and one-on-one instruction.

Interventions were provided at home from March-August; however, limited progress was noted by her parents and she was enrolled in preschool for the 2019-2020 school year so that additional interventions could be provided. The participant began receiving Tier III interventions at the beginning of the school year by her classroom teacher. Shortly after her fourth birthday, her preschool teacher referred her for an evaluation to determine eligibility for special education services. The Admissions and Release Committee (ARC) wished to consider the criteria for

Developmental Delay due to her below average skills in the areas of communication and cognition.

While obtaining the participant's case history from her mother, she indicated that at home, the participant became easily overstimulated in play, overacted when faced with problems, and had a short attention span. It was also reported that the participant prefers to play alone and that her least favorite activity would be anything in group settings. According to her mother, the participant was characterized as being funny and sweet, while also being strong-willed and stubborn. To discipline inappropriate behaviors, her mother reported using techniques of ignoring the problematic behavior, reasoning with her, redirecting her attention, or spanking her. The participant's strengths were identified as being able to work independently and having good motor skills.

The *Preschool Language Scales, Fifth Edition (PLS-5)* was administered by the school speech-language pathologist to assess the participant's ability to use language for a variety of purposes. Table 8 indicates that her language abilities were in the fifth percentile when compared to other children her age. The assessment's receptive domain indicated strengths in identifying colors, understanding spatial concepts, understanding use of objects, and recognizing actions in pictures. Her weaknesses in this domain included making inferences in addition to understanding negation, pronouns, and analogies. Expressively, the participant demonstrated her ability to use four-to-five-word utterances, appropriately use plurals, name pictures and objects, and use a variety of words. Weaknesses in expressive language included answering "wh" questions, using present progressive -ing, naming described objects, and using possessives.

Additionally, an assistive technology screener was completed to determine if there was a potential need for assistive technology to improve the participant's functioning. Results provided

in Table 9 indicate the areas in which deficit skills were found. Based on these findings, it was not deemed necessary to further evaluate for assistive technology.

**Table 8**

*PLS-5 Results*

<b>Area</b>	<b>Standard Score</b>	<b>Percentile</b>
Receptive Language	71	3
Expressive Language	82	12
<b>Total Language</b>	<b>75 (z= -1.70)</b>	<b>5</b>

**Table 9**

*Assistive Technology Screening Results*

<b>Age-Appropriate Skills</b>	<b>Skill Deficits</b>
Physical Functioning/Motor Abilities	Fine Motor Skills
Communication Functioning	<ul style="list-style-type: none"> <li>● Handling Scissors</li> </ul>
Vision	<ul style="list-style-type: none"> <li>● Using Craft Materials</li> </ul>
General Health	<ul style="list-style-type: none"> <li>● Using Clothing Fasteners</li> </ul>
Functional Skills	<ul style="list-style-type: none"> <li>● Using a Computer Mouse</li> <li>● Copying Basic Designs</li> </ul>
	Academic Functioning
	<ul style="list-style-type: none"> <li>● Understand Basic Cause/Effect</li> <li>● Have the Attention Span to Complete a Task</li> </ul>
	Sensory Functioning
	<ul style="list-style-type: none"> <li>● Handling Transitions</li> </ul>

In addition to the communication assessment, the cognitive domain of the *Battelle Developmental Inventory, Second Edition, Normative Update (BDI-2-NU)* was administered to the participant by her teacher to assess her cognitive functioning. Table 10 summarizes her performance on this assessment. She was able to locate hidden items in a picture scene, recall familiar objects taken from her view, identify the source of common actions, name basic colors, and identify big and little shapes. At the time of the evaluation, the participant was not yet able to attend to a learning task for five minutes, repeat a three-digit sequence, or sort objects by size or shape.

**Table 10**

*BDI-2-NU Results*

<b>Domain/Subdomain</b>	<b>Standard Score</b>	<b>Z-Score</b>	<b>Percentile</b>	<b>Description</b>
<b>Cognitive</b>	61	-2.6	1	Significant Delay
Attention & Memory	1			Significant Delay
Reasoning & Academic Concepts	4			Mild Delay
Perception & Concepts	3			Significant Delay

Based on formal and informal evaluation results and the *Kentucky Eligibility Guidelines (KEG)* criteria, the participant received a communication severity rating of two, indicating a moderate language impairment. Although speech, fluency, and voice were found to be within normal limits, her language weaknesses were deemed to adversely affect the participant's ability to communicate her thoughts, feelings, and ideas across communication settings and partners. Additionally, cognitive deficits were likely to impact her educational performance. Evaluation recommendations were for the ARC to review the assessment results, past school records, and

previously received academic interventions to determine appropriate educational programming for the participant.

### ***Individual Education Program (IEP)***

The participant's cognitive and communication skills were more than 1.5 standard deviations below the mean for her age, qualifying her for the diagnosis of Developmental Delay according to Kentucky Eligibility Guidelines and *IDEA*. To address any adverse impacts her communication and cognition would have on her functioning, an IEP was composed by the ARC documenting all specifications regarding the provision of special education services. In order to place the participant in her least restrictive environment while receiving services, her IEP indicated that she would participate in special education and speech/language services within her preschool classroom. Twenty minutes of special education services were allocated each day, while a minimum of 30 minutes of language therapy would be provided four times a month.

Four goals were outlined within the document with specially designed instructions being provided for each. The participant's goals included correctly responding to "who", "what", and "where" questions, accurately using present progressive -ing in sentences to describe what objects or items are doing, remaining on task during small group activities with minimal support, and counting objects 1-10 and accurately stating the total. At the ARC's annual review meeting, the participant's progress toward these goals will be discussed and the IEP will be amended as deemed appropriate.

### **Present Day**

The participant is now five years old. She continues to receive special education and speech therapy services from her public preschool as outlined in her IEP. Concurrently, she attends weekly sessions focused on increased language skills including, understanding and use,

at the university clinic. Her current therapy goals include correctly answering wh- questions, using intelligible three-to-four-word utterances to make up 80% of her utterances, and the receptive understanding and expressive use of prepositions. At this time, the participant's mother indicates that she has noticed improvements in her daughter's communication since beginning services, such as expanded sentence length, improved vocabulary, and increased spans of sustained attention to tasks.

## Chapter 5: Discussion

Upon the compilation and analysis of relevant data in the participant's diagnostic journey, answers to the research questions were obtained. The discussion section provides insight to each question, comparing findings from the case study with external research within the field of speech-language pathology.

### **1. What systemic procedures, if any, were effective in identifying the participant as being at-risk for autism spectrum disorder or developmental delay including communication concerns?**

It is recommended by the American Pediatric Association for the *M-CHAT* to be completed at the ages of 18 and 24 months (CDC, 2020b). The participant's pediatrician administered the screening at her 15-month well-child visit. Concerns about her failing score was the official starting point of her diagnostic journey, which resulted in referrals to other practitioners for further evaluations. Since her pediatrician was proactive in early detection, the participant was able to begin receiving early intervention more promptly than if he would have waited another three months. In addition to an early intervention referral, the pediatrician also referred the participant for a hearing screening and a CEC evaluation at Vanderbilt. The referral to multidisciplinary professionals is supported by research indicating the importance of evaluating an individual holistically to ensure the best possible identification of impairments within various scopes of practice (ASHA, 2020a).

The participant and her family followed up with the referrals to First Steps, which completed an evaluation and provided needed services, and a hearing screening. These systemic procedures were effective in identifying the participant as having possible developmental deficits. However, the CDC states that if a screening indicates potential concerns, then a formal

developmental evaluation should be completed (CDC 2020a). In this case, the participant did not follow up with Vanderbilt to receive a comprehensive evaluation. Thus, she did not complete a formal ASD evaluation despite her persistent failure on two administrations of the *M-CHAT-R*.

## **2. What role did the caregivers have in the diagnostic process?**

The participant's parents played a significant role in her diagnostic journey from the very beginning. The first people to notice potential developmental concerns in the participant were her parents. Because her mother had experience with other children, she was able to compare her daughter's abilities with those of the children she had encountered. Without the detection of these atypical behaviors, it is possible that her developmental concerns may not have been addressed until she was older. Similarly, if the participant's parents had not made well-child visits a priority and consistently attended scheduled appointments, referrals to early intervention services would not have been made, potentially further delaying her communication. Attending and scheduling evaluations, appointments, and services are dependent upon caregivers (Lappé et al., 2018; Smith-Young et al., 2020). Access to healthcare and understanding the importance of well-child visits can serve as a barrier to early detection and diagnosis of various disorders, such as ASD. Some families may not have reliable transportation to travel to and from appointments while others may not have the financial means necessary for their copays. Others may not be able to take time off from their work to get to an appointment for their child who does not have any physical sickness so that they can save up their time off for when they deem it vital.

Fortunately, in the participant's case, her parents were attentive to their daughter's needs and followed up with the recommended early intervention, hearing, and speech-language referrals. Although the pediatrician provided the participant's parents with referrals to specific locations and services, they had to initiate the diagnostic process by making phone calls to each

location, scheduling the needed services, and taking her to the appointments. Families may struggle with this process as there are so many things to coordinate and schedule. In this case study, however, the participant's parents appropriately facilitated the process, attending evaluations, filling out paperwork, and answering interview questions, resulting in their daughter's diagnoses of developmental delay and language disorder.

Parents play a critical role and in this case study; the parents consistently followed through with professional recommendations to seek evaluation and intervention services. While parents are essential, they are under the guidance of professionals and operate under the assumption that the referrals and services provided are appropriate and inclusive. It should be noted that the first evaluation the family sought out was not with a speech-language pathologist, but rather a psychologist, who did not collaborate with a speech-language pathologist. When seeking a diagnosis of any disorder with communication deficits, such as ASD, speech-language pathologists should be working with the multidisciplinary team to assess the communication components of the diagnosis.

Perhaps if the caregivers would have followed up with the referral to receive a comprehensive interdisciplinary evaluation at Vanderbilt, the participant's diagnostic journey may have been simplified, removing the need for additional assessments and creating a more inclusive and specialized plan of care. With the detailed information provided from a comprehensive interdisciplinary evaluation for ASD, the participant may have received a diagnosis of ASD, and the evaluation report would have outlined suggested supports and guidance for services. Perhaps with that information, her caregivers would have transitioned her immediately from First Steps to preschool to ensure that there was no lapse in services. Additionally, it should be noted that a referral to a specialized clinic, such as Vanderbilt in this

case, could be difficult for many families to follow through with secondary to constraints on time, finances, and transportation. Residing in a rural area often results in extended travel to urban areas in order to receive comprehensive, multidisciplinary diagnostic services.

### **3. What role did the caregivers have in obtaining therapeutic services?**

Not only did the participant's caregivers take her to several appointments for various evaluations to receive her diagnoses, but they remained diligent in their efforts to provide for their daughter. Once it was determined that the participant would benefit from receiving services, her parents acted without delay and got her enrolled in First Steps. The decision to seek out and receive services may seem indisputable, but many families face several barriers when coordinating a plan of care for their child, whether it be finances, a lack of local service providers, or being unsure where to begin (Lappé et al., 2018; Smith-Young et al., 2020).

After the participant aged out of early intervention services, her parents had to determine what step they would take next. Unlike First Steps, who provided both the initial evaluation and services, her parents now had to decide for themselves where to take their daughter to receive the services they knew were warranted. The process of transitioning to a different provider entails another round of evaluations before services can be initiated. The participant's parents located an outpatient facility, scheduled the initial evaluation, and decided that their daughter would be receiving services at this location.

The family then found themselves making hour-long trips to speech-language therapy sessions each week for four months. Since both of her parents have jobs, this accessibility issue could have served as a much greater barrier to services. Smith-Young et al. (2020) found that more than half of the families with a child with an ASD diagnosis experience disruptions in employment due to child-care difficulties and other autism-related scenarios in the past year.

While the participant does not have a diagnosis of ASD, there were still financial burdens and time demands placed on her parents in order to provide necessary services. Monetary and time constraints placed on families could potentially cause consequential disruptions in employment and finances (Martinez et al., 2018; Zuckerman et al., 2015). Fortunately, the participant's parents and other family members were able to coordinate their schedules and work together to see that the participant had regular attendance at therapy sessions since the initiation of services. While the participant's family reported having a positive experience in regard to diagnosis and receiving interventions, many others in this role are not as fortunate (Smith-Young et al., 2020).

**4. Is the participant currently receiving supports necessary to be successful in improving communication skills across settings?**

Upon entering preschool, the participant had an Individualized Education Program developed to facilitate her communication in the academic setting. In the least restrictive environment of the preschool classroom, she is currently receiving a minimum of 30 minutes of language therapy four times per month by the school speech-language pathologist. Her current IEP goals include answering "who", "what", and "where" questions and correctly using present progressive -ing. Specially designed instructions used during therapy sessions include auditory bombardment of language targets, verbal prompts, visual cues, recasts, expansions, questioning techniques, and direct instruction.

Outside of school, the participant continues to receive language interventions from a university clinic, where she has made consistent communicative progress each semester. Presently, her objectives include answering "wh" questions, consistently producing three-to-four word intelligible utterances, and demonstrating receptive understanding and expressive use of prepositions. During the participant's time at the university clinic, multiple clinicians have

reported the effectiveness of using visual supports in sessions. Visual timers and schedules worked to eliminate protesting behaviors during times of transition between activities and the ending of appointments. Additionally, the implementation of visual cues throughout interventions to provide visual representations of expectations, choices, and prompts were more efficient than the provision of any verbal information. Fading of these visuals has shown to improve the participant's communicative performance both expressively and receptively.

Since the initiation of therapeutic services, the participant's mother has noted progress in her daughter's communication. Notable improvements include expanded utterance length, improved lexicon, and longer durations of sustained attention. Due to early detection, early intervention, provision of current services, and her supportive family, her prognosis is very positive at this time. If, in the future, the participant begins to regress or demonstrate a lack of progress in the area of communication, it is not out of the realm of possibility that the diagnosis of ASD would need to be revisited. Throughout her diagnostic journey, she never received an evaluation specifically assessing for ASD with an interdisciplinary team.

As noted in the review of the literature, females have a higher likelihood of being misdiagnosed or remaining undiagnosed when the true diagnosis is ASD (Cridland et al., 2013; Bargiela et al., 2016; Volkens, 2018). Studies have been completed on the thoughts and experiences of females who received a diagnosis of ASD later in life. These studies include reports of females who had previously received a diagnosis of obsessive-compulsive disorder, anxiety disorder, depression, or eating disorders, when in reality, their ASD was presenting with characteristics similar to those found in such disorders (Volkens, 2018). Still yet, other females, who may have more covert characteristics of ASD, may go undetected or undiagnosed completely until they are adults and can advocate for themselves, understanding that there could

be an underlying cause to their personality and behaviors (Bariégla et al., 2016). Similarly, this could be the case for the participant or any young female who has not received a diagnosis of ASD.

### **Implications**

Results from this case study indicate the importance of several facets within the scope of practice of speech-language pathologists. Advocacy and education pertaining to developmental delays, early intervention, and diagnostics should be more widely promoted to the general public. The participant's mother mentioned in an interview that "No one talks about delays." It is up to speech-language pathologists to advocate for young children and shed light on the important period before communication disorders are formally diagnosed and are classified as delays. Advice for caregivers on facilitating language skills and promoting communication should be readily available. Similarly, the "wait and see" approach to intervention should be collectively dismissed. The relationship between neural connections, learning, and age is clearly understood (CDC, 2020a). Therefore, professionals should be sharing this knowledge and advocating for early detection and intervention of all young children regardless of socioeconomic status, culture, or background.

Further evidencing the importance of early detection and intervention, the benefit of well-child visits was highlighted in the study. The participant's parents prioritized these visits, which was where her diagnostic journey began. While some may think that these appointments are trivial, it can be seen in the participant's case that these visits promote detection of potential developmental delays. As in the participant's experience, the administration of the *M-CHAT-R* may not only be helpful in identifying ASD, but it may also detect underlying characteristics

such as language or other developmental impairments. Early detection facilitates early intervention, which promotes development and optimizes outcomes (CDC, 2020a).

Regarding diagnostic procedures, more research and tools are needed to increase the efficiency and effectiveness of obtaining a diagnosis or lack thereof. While the DSM-V provides diagnostic criteria for ASD and communication disorders, there is an obvious lack of explicit details describing what steps should be taken to pursue a potential diagnosis. The development of an unambiguous plan of action for diagnosing ASD could be beneficial to healthcare professionals and families alike, lowering the incidence of individuals going undiagnosed. Another pivotal development would be more inclusive screeners and assessments. Normed populations for available evaluation materials are not representative of females nor minorities. Psychometric properties of sensitivity and specificity should be improved to further identify individuals with ASD in an efficient manner, preventing diagnostic delay.

Another outcome of this study is understanding how paramount caregivers are in the diagnostic and treatment processes for any disorder. Without advocates and financial resources, individuals with ASD, developmental delays, or communication disorders may go undiagnosed or untreated and face the adverse impacts of such experiences. Even if there was a specific diagnostic route and appropriate, inclusive diagnostic instruments; without caregivers initiating and following through with each step in the diagnostic journey, children would reap no benefits from these developments.

### **Limitations**

The limitations of this research include the limited sample size. Although the analysis of a single case is beneficial to the field of speech-language pathology, the participant and her family's experiences cannot be generalized to the entire population of female preschoolers with

developmental delays. Further, her mother's experience with other children and ability to compare her daughter's development with others is not always commonplace. When combined with the proactive nature of her parents, the diagnostic journey of the participant cannot be deemed as the typical path that all families take. While the participant resides in rural Kentucky, her residence near a university clinic prevented her family from facing a more severe accessibility barrier. A final limitation is the brevity of this case. A longitudinal study of the participant's growth, development, and communicative journey could provide further insight into the area of developmental delay and communication disorders.

### **Recommendations for Future Research**

Future studies with similar research questions could be completed with a larger sample size. The inclusion of more participants with similar diagnoses of developmental delay would provide additional information that could contribute to the development of a diagnostic route for ASD. Similarly, conduction of a longitudinal study following the diagnostic routes of a small group of female toddlers who have failed the M-CHAT would generate valuable information. If it were found that multiple families were experiencing similar barriers and frustrations, their trials could be used to prevent further difficulties for families in the future. It could also be found that accessibility, whether it be financial or locational, may be the biggest hindrance to the diagnostic and treatment processes, calling for increased services providers and coverage. To focus in on the disparity between males and females, another variation of the study focusing on the diagnostic experiences of females compared to males with ASD may yield beneficial data to assist in the creation of a more representative diagnostic instrument improving the experiences of the female population.

## **Conclusion**

Overall, the participant in this case study, along with her family, reported a satisfactory diagnostic journey resulting in appropriate supports to facilitate her communicative success. However, it is recognized that this is not the case for many individuals. In order for advancements to be made in the effectiveness and efficiency of diagnosing ASD or lack thereof in young females, more research should be conducted. Until the diagnostic procedures are improved upon, children, particularly females, with ASD will continue to go undetected, resulting in a variety of negative communicative consequences. It should also be noted that speech-language pathologists should play an essential role in the interdisciplinary team that diagnoses ASD. In order to meet the ASD criteria, a communication impairment must be present, indicating the importance of a professional with the realm of communication being in the scope of practice. In other circumstances, in an absence of ASD, consultation with a speech-language pathologist should be undeniable when a communication impairment is suspected. Perhaps the initial referral made in a case of suspected ASD should be to a speech-language pathologist and not only a psychologist to ensure that the communication component of the disorder is appropriately evaluated and addressed.

## Appendix A. Institutional Review Board Approval



### Research Participation Consent Form

**Study Title:** Exploring the Diagnostic Journey of a Preschool-Aged Female: A Retrospective Case Study  
**Primary Investigator:** Lindsay Crafton, Graduate Student Investigator  
**Co-Investigators:** Stephanie Schaaf, Ed. D, CCC-SLP, Alison Brown, CCC-SLP, Amanda Duncan, CCC-SLP  
**Faculty Sponsor Contact:** Dr. Stephanie Schaaf, 270-809-3783, sschaaf@murraystate.edu

Your child is being invited to participate in a research study conducted through Murray State University. This form contains information you will need to help you decide whether to be in this research study or not. Please read the form carefully and ask the study team member(s) questions about anything that is not clear. You will be given a copy of this form to keep.

1. **Nature and Purpose of Project:** The purpose of this study is to investigate the diagnostic route of a preschool-aged female with communication deficits and explore her journey to seek and receive services.
2. **Participant Selection:** Your child is asked to participate because she has been suspected to have communication disorders and has been evaluated by various professionals.
3. **Explanation of Procedures:** This study will be used for research purposes. The study activities include analysis of evaluations and reports from your child's medical and educational personnel, which may include pediatrician, psychologist, speech-language pathologist, and school system.  
**Study duration:** You will be asked to mail in copies of your child's developmentally relevant reports in a pre-addressed envelope that will be provided to you. A phone interview will take approximately one hour to obtain any additional pertinent information regarding the study.
4. **Recordings/Photographs:** Recordings of previous therapy sessions may be reviewed with parental consent. There will be no current face-to-face sessions, therefore no new recordings or photographs will be obtained.  
  
 I agree to allow the study team members to review previously recorded therapy sessions.  
*Initials*  
  
 I do not allow the study team members to review previously recorded therapy sessions.  
*Initials*
5. **Discomforts and Risks:** There are no anticipated risks and/or discomforts for participants.
6. **Benefits:** This study is not designed to benefit you or your child directly. However, your child's participation may help to increase our understanding of the evaluation and diagnostic process that children with communication deficits and their families may experience.

7. **Confidentiality:** Your child's identity will be known to the researchers, but the information you provide will be kept confidential. Any written research on this case study will not include the name of you or your child. All data that is collected will be stored in a locked filing cabinet in 111 Alexander Hall. Any digital information will be stored on an encrypted flash drive, also placed in the locked filing cabinet. All data will be shredded and destroyed when your child reaches one year past the age of 18.
8. **Refusal/Withdrawal:** Your child's participation is strictly voluntary, and you are free to withdraw/stop participating at any time with absolutely no penalty. During the phone interview, any questions may be skipped if you would prefer not to answer.
9. **Contact Information:** Any questions about the procedures or conduct of this research should be brought to the attention of Dr. Stephanie Schaaf at 270-809-3783 or [sschaaf@murraystate.edu](mailto:sschaaf@murraystate.edu). If you would like to know the results of this study, please contact Dr. Stephanie Schaaf.

Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in this study.

The dated approval stamp on this document indicates that this project has been reviewed and approved by the Murray State University Institutional Review Board (IRB) for the Protection of Human Subjects. If you have any questions about your rights as a research participant, you should contact the MSU IRB Coordinator at (270) 809-2916 or [msu.urb@murraystate.edu](mailto:msu.urb@murraystate.edu).

Participant's Name (printed): \_\_\_\_\_

\_\_\_\_\_  
(Parent/Guardian/ Legally Authorized Representative) (Date)

\_\_\_\_\_  
(Signature of Person Obtaining Consent) (Date)



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