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PARENT AND EVALUATOR EXPERIENCES ACCESSING SERVICES FOR  
CHILDREN ON THE AUTISM SPECTRUM

by

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## **Dedication**

To my family for always loving and supporting me

## **Acknowledgments**

I cannot thank my family enough for supporting me in the pursuit of my doctoral degree. Without their understanding and encouragement, I would not have been able to complete my dissertation. I want to thank my parents for always supporting my academic endeavors. Thank you to my mother for instilling in me a love of reading that has been invaluable in my life. Thank you to my father for always having my back. I want to especially thank my husband for being my biggest supporter and cheerleader. You are my everything, and I am so blessed to have you in my life. More than once, you kept me going when I didn't know if I could finish. My children, Jakob, Nathan, and Madison are my motivation for continuing to improve and better myself. I want them to know that with hard work, they are capable of anything.

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ABSTRACT

PARENT AND EVALUATOR EXPERIENCES ACCESSING SERVICES FOR  
CHILDREN ON THE AUTISM SPECTRUM

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University of Houston-Clear Lake, 2022

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The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD and gain insight into additionally needed services for children with ASD. This qualitative study interviewed four parents and five examiners about their experiences working with families of children with ASD. The researcher then analyzed the data by coding and categorizing to determine salient themes. The most prominent barriers across evaluators and parents were limited knowledge of ASD, service accessibility, and difficulties navigating the system. The findings are centered on the need to provide more extensive and individualized support for families, increasing and enhancing service availability for children diagnosed with ASD, and an intentional focus on meeting the unique needs of diverse families.

## TABLE OF CONTENTS

CHAPTER I: INTRODUCTION.....	1
Research Problem .....	1
Significance of the Study .....	2
Research Purpose and Questions .....	3
Definition of Key Terms .....	3
Conclusion .....	4
CHAPTER II: REVIEW OF THE LITERATURE .....	6
Autism Spectrum Disorders .....	7
Evaluation for Autism Spectrum Disorders .....	8
Medical Diagnosis versus Educational Eligibility .....	9
Individuals with Disabilities Education Act (IDEA) .....	10
Current Prevalence and Demographic Data.....	11
Child Find .....	12
Interventions for ASD.....	14
Barriers.....	15
Age of Diagnosis.....	16
Gender.....	16
Socioeconomic Status Barriers .....	18
Cultural and Ethnic Barriers .....	20
Parental Barriers.....	25
Physicians .....	28
Provider Bias.....	29
Theoretical Framework.....	31
Conclusion .....	32
CHAPTER III: METHODOLOGY .....	34
Overview of Research Problem .....	34
Research Purpose .....	35
Research Questions .....	35
Research Design.....	35
Participant Selection .....	35
Data Collection .....	36
Interviews.....	37
Data Analysis .....	37
Validity .....	38
Privacy and Ethical Considerations .....	38

CHAPTER IV: RESULTS.....	39
Description of the Participants.....	39
Portrait of the Participants and Experiences .....	41
Parent Participants .....	41
Lisa.....	41
Catherine.....	46
Jessica .....	49
Robert.....	53
Examiner Participants .....	55
Alice.....	55
Lyn .....	57
Jane .....	60
Sandra .....	62
Jenny .....	63
Barriers to Obtaining Services .....	67
Limited Knowledge of ASD .....	68
Service Availability .....	70
Working with Families from Diverse Backgrounds .....	77
Summary .....	81
CHAPTER V: CONCLUSION .....	83
Summary of the Study .....	83
Findings and Discussion .....	83
Parents need more support.....	84
Parents need increased service availability.....	85
Families from diverse backgrounds have different values and require different supports.....	88
Recommendations for Application .....	89
Increased Practitioners and Service Providers.....	90
Service Coordination .....	91
Increased Opportunities for Early Childhood Education.....	91
Increased Knowledge and Understanding of Different Cultures .....	92
Recommendations for Future Research.....	93
Limitations .....	94
Conclusion .....	94
REFERENCES .....	96
APPENDIX A: PARENT SURVEY COVER LETTER.....	111
APPENDIX B: EVALUATOR SURVEY COVER LETTER.....	112
APPENDIX C: PARENT INTERVIEW QUESTIONS .....	113



APPENDIX D: EVALUATOR INTERVIEW QUESTIONS..... 115

LIST OF TABLES

Table 4.1: Demographic Data of Research Participants ..... 40  
Table 4.2: Demographic Data of Evaluator Research Participants..... 40

## CHAPTER I: INTRODUCTION

In the United States, there is a persistent gap between the percentage of children eligible to receive early childhood services and the percentage of families who access the services (Gennetian et al., 2016). This lack of service utilization is especially concerning for children with autism spectrum disorders (ASD) who experience deficits in communication and socialization that are lifelong (Mayo Clinic, 2018). Research supports that early intervention can reduce the presentation of autism symptomatology, and children receiving early intervention may require fewer services over time (Dawson, 2008; Guralnick, 2011). Many children with developmental and behavioral concerns are not identified as early as possible, resulting in a delay in accessing services in their social and educational settings (Center for Disease Control [CDC], 2020a). This delay in diagnosis can compound the developmental delays with missed opportunities for intervention (Clark et al., 2018; CDC, 2020a).

### **Research Problem**

Delays in receiving diagnostic and intervention services for children with ASD can significantly impact the child's development over time. The earlier appropriate intervention is determined and initiated, the better the prognosis is for the child's future. Research has shown that early intervention can lessen the effects of the full presentation of ASD symptomatology (Dawson, 2008). Therefore, it is critical children begin receiving interventions early to maximize a child's progress.

Clark et al. (2018) investigated outcomes of 48 children who received early diagnoses of ASD and 37 children who received later diagnoses. Children diagnosed before three years of age were considered early, and children diagnosed after three were considered later. The study showed that early diagnosis leads to earlier access to

interventions and better overall cognitive and verbal skills for school-age children. Children diagnosed early were more likely to have less restrictive educational placements and required less continued support than those diagnosed later. Thus, promoting the most positive school outcomes for children due to their increased ability to access early intervention (Clark et al., 2018). When examining the quality of parent and child interactions before and after an autism diagnosis, Suma et al. (2016) found that, on average, children diagnosed early were more likely to have increased intervention services than children who were not yet diagnosed with ASD. However, the type and number of interventions they could access were less than optimal. Even with early diagnosis and increased interest in services, parents still experience barriers accessing services due to the high demands for interventions resulting in waitlists that limit a family's ability to access needed services (Clark et al., 2018). Determining the barriers that prevent families from accessing services is critical to minimizing the delays in accessing critical services.

Research has shown the significant benefits of early intervention for children with ASD to reduce symptomatology over time. Nevertheless, children with ASD continue to be diagnosed at later ages. As a result, they cannot optimize the years of services they would receive with earlier diagnosis and service initiation (Dawson, 2008; Suma et al., 2016; Heath et al., 2018). The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD and gain insight into additionally needed services for children with ASD.

### **Significance of the Study**

Determining barriers to accessing services for children with ASD through parent and evaluator experiences helps identify and fill gaps in service and allows children to receive interventions earlier. This information can also drive policy and help early

intervention programs, pediatricians, and local education agencies improve child find practices and increase access to intervention services. Parent and evaluator experiences accessing services for children with ASD allows further insight into why children are always not accessing early intervention services, thus enabling more effective future planning.

### **Research Purpose and Questions**

The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD and gain insight into additionally needed services for children with ASD.

1. What are parent experiences accessing services for children on the autism spectrum?
2. What are evaluators' experiences working with children to access services for children on the autism spectrum?
3. What additional services and supports do parents feel would benefit their children on the autism spectrum?
4. What additional services and supports do evaluators feel would benefit children on the autism spectrum?

### **Definition of Key Terms**

For the intended study, the following terms will be utilized throughout the document.

*Autism Spectrum Disorder:* Autism spectrum disorder (ASD) refers to a group of neurodevelopmental disorders involving impairments in social interaction and communication, as well as the presence of repetitive or stereotyped behaviors (Durkin et al., 2010, American Psychological Association [APA], 2013).

*Access:* To use, obtain or make use of something (Merriam-Webster, 2020a). In this study, access will be used in the context of parents obtaining diagnostic and use of intervention services for children with ASD.

*Barriers:* Something immaterial that impedes or separates (Merriam-Webster, 2020b). In this study, barriers will be used in the context of anything that prevents parents from accessing needed diagnostic and intervention services for their children with ASD.

*Educators:* Persons responsible for providing educational instruction to children (English, 2009). This definition includes not only public-school personnel but anyone who provides educational instruction to children.

*Evaluators:* For this study, evaluators will be used to describe school psychologists/licensed specialists in school psychology, along with other specialized instructional support personnel, as providing assessment and evaluation services as part of a comprehensive program for students with disabilities (National Association of School Psychologists [NASP], 2016).

*Experiences:* The total of the conscious events that make up an individual life or the past of a community, nation, or humankind, generally something that one has done or lived through. (Merriam-Webster, 2020c). For this study, experiences will focus on those experiences in the diagnostic process and accessing services for children with ASD.

*Parent:* Person who provides care and makes educational decisions for a child (Heath, 2006). This term includes all those who identify themselves as parents even if they do not have legal guardianship.

## **Conclusion**

Children diagnosed with ASD must begin interventions as soon as possible to curb the effects of the disorder (Dawson, 2008; Guralnick, 2011). The purpose of this qualitative study was to gather parent and evaluator experiences accessing services for

children with ASD to determine barriers and what additional services are needed. This research can help children receive intervention sooner and improve outcomes for children with ASD.

## CHAPTER II: REVIEW OF THE LITERATURE

Autism spectrum disorders (ASD) result in social and communication deficits that are lifelong and affect those with the disorder into adulthood (Mayo Clinic, 2018). Research shows that autism can be improved with intervention, and thus children may need fewer services over time (Dawson, 2008; Guralnick, 2011). It is critical that screening, evaluating, and diagnosing children with ASD occur as early as possible to ensure students receive support and services to reach their full potential (Center for Disease Control [CDC], 2020c). Early intervention has been shown to lead to better outcomes for children with ASD (Suma et al., 2016). Early diagnosis leads to earlier access to interventions, better cognitive and verbal skills for school-age children. Students who receive early interventions are more likely to have a less restrictive placement and require less continued support than children diagnosed later and do not receive those early supports (Clark et al., 2018). Duncan & Magnuson (2013) reviewed research related to the expenditures on early childhood education programs and the social investments in children and their outcomes. They found that programs overall support a boost of cognitive abilities and early childhood achievement.

The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD and gain insight into current needs and additionally needed services for children with ASD. This chapter provides an overview of ASD, evaluation, and interventions for ASD, the Individuals with Disabilities Education Act (IDEA), and barriers to accessing and using services for children with ASD.

## **Autism Spectrum Disorders**

An autism spectrum disorder (ASD) is a developmental disorder that impacts socialization and occurs in conjunction with repetitive and stereotypical behavior and interests that have a variable impact on communication and intellect (Blacher & Christian, 2011). Autism Spectrum Disorders (ASD) cause significant communication, social and behavioral challenges (APA, 2013; Center for Disease Control [CDC], 2020c). Children and adults with autism often have difficulties with their communication, behavior, and social skills. They may engage in repetitive behaviors and have difficulties with changes in daily activities. They may also have different ways of attending, learning, and reacting to their environment (APA, 2013; CDC, 2020c). Early symptoms of autism may include having little interest in caretakers and children, avoiding eye contact, limited language, and distress during minor changes in routine (CDC, 2020c). Ghanouni et al. (2019) investigated perceived barriers to participation for children with ASD from relative stakeholders such as parents of children with ASD, youth with ASD, and clinicians. Several themes emerged that made it difficult for children with ASD to participate in educational settings. These include difficulties understanding and navigating social situations, limited training in engaging in social interactions, and engagement in maladaptive behaviors (Ghanouni et al., 2019).

Data gathered from 2009 to 2017 shows that one in six (17%) children aged three to 17 years were diagnosed with a type of developmental disability (Zablotsky et al., 2019). As of 2016, research conducted by the Center for Disease Control's (CDC) Autism and Developmental Disabilities Monitoring (ADDMM) Network found that one in 54 (1.9%) of 8-year olds were diagnosed with ASD in the United States (CDC, 2020a; Maenner et al., 2020). This reveals an increase in prevalence since 2000, which found that approximately one in 150 8-year-olds were diagnosed with ASD (CDC, 2020a).



Currently, the global rate for ASD is reportedly between 3-6 children per 1000, though it is difficult to compare ASD prevalence across countries due to different methodologies (Kassim & Mohamed, 2019). The growing rate of children diagnosed with ASD is linked to better diagnostic criteria, but a rise in ASD diagnoses cannot be ruled out. The etiology of autism based on current research appears to be related to genetic mutations and some still-unknown environmental factors (Rutter, 2005).

Autism Spectrum Disorders (ASD) are usually diagnosed around the age of three, with growing evidence for symptoms of ASD being present after two months of age. Jones and Klin (2013) researched early autism symptoms and found that children with ASD show a decrease in eye gaze fixation starting between two and twenty-four months that is not present in children who do not have the disorder. The steeper the decline in fixation results in a more severe disorder presentation (Jones & Klin, 2013). ASD occurs across all ethnic, racial, and socioeconomic groups (Maenner et al., 2020), with current research showing no overall difference in the diagnosis of Black children when compared to White children; however, there is still a reduced number of Hispanic children diagnosed with ASD compared to their Black and White counterparts (CDC, 2020a). Of children diagnosed with ASD, around one-third also had an intellectual disability (CDC, 2020a). Boys are four times more likely to be diagnosed with autism than girls (Maenner et al., 2020). Current research from the ADDM Network found that children born in 2012 were more likely to have an ASD diagnosis by four years of age than children born in 2008 (CDC, 2020b).

### **Evaluation for Autism Spectrum Disorders**

Current recommendations for ASD screening and evaluation include an ASD screener that the physician utilizes that is archived in the child's medical records (Landa, et al., 2013). At the first sign of atypical development, a referral should be made for

further developmental assessment (Landa et al., 2013). A study conducted by Zwaigenbaum and colleagues (2015) found no consistent, reliable markers for ASD before 12 months of age. However, dysfunction in social communication and atypical behaviors are typically observable between 12 and 24 months of age. With current research indicating the presence of symptomatology before a child's third birthday, interventions must begin as soon as possible to remediate the developmental delays (Dawson, 2008). There is no medical test to diagnose ASD, and severity and symptomatology can vary greatly, making diagnosis difficult (Mayo Clinic, 2018). Due to these difficulties, evaluations for autism may include observations, structured social and communicative interactions, and information from other specialists. A child's symptomatology is reviewed against the criteria outlined in the DSM-5. Genetic testing is also often recommended to rule out other disorders such as Fragile X and Rett Syndrome, which can be closely associated with autism. There is no current cure for autism, and intervention needs vary from person to person to minimize autism symptomatology and support learning and development (Mayo Clinic, 2018).

### **Medical Diagnosis versus Educational Eligibility**

Parents seeking services for their children with ASD are often surprised to find differences in a medical diagnosis versus educational eligibility for services (CAR, 2020). A medical diagnosis alone does not mean that a student will automatically receive educational services. For a student to receive educational services, they must meet the criteria for a specific disability and have an educational need for services (Center for Autism Research [CAR], 2020). A medical diagnosis is usually made by a physician or other trained clinician using the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Children must exhibit several symptoms, including difficulties with social interactions and repetitive behaviors (CAR, 2020). Educational eligibilities

are determined by a team of school professionals as well as the student's parents. For a student to qualify, they must meet disability criteria for one of the 14 outlined disability conditions under IDEA, which also has an adverse educational impact (CAR, 2020). IDEA eligibility for special education services is a two-pronged approach meaning that a student may have a medical diagnosis of autism, but if the student does not require specialized instruction to progress in their education, they may not be eligible for special education. Services in the educational setting focus on functional and academic skills, while services in a private setting may address skills more globally. Educational services are determined by an Individual Education Program (IEP) team that determines educational supports and services and a plan for meeting a student's needs (CAR, 2020).

### **Individuals with Disabilities Education Act (IDEA)**

The Individuals with Disabilities Education Act of 2004 (IDEA 2004) is a federal law that ensures students with disabilities receive a free and appropriate education (FAPE) that is individually designed to meet their individual needs (ECTA, n.d.; IDEA, 2004). Part A outlines the general provisions of the law. Part B pertains to providing FAPE for children with disabilities in the least restrictive environment (LRE) (Early Childhood Technical Assistance Center [ECTA], n.d.; IDEA, 2004). Part C of IDEA delineates early intervention services for children birth to 36 months of age. (Centers for Disease Control and Prevention (CDC), 2019a; IDEA, 2004). Part C is a federal grant program that assists states in operating comprehensive systems of early interventions statewide for infants and toddlers (ECTA, n.d.; IDEA, 2004). Possible services for children include counseling and home visits, family training, speech, occupational or physical therapy, hearing, nutrition, health, service coordination, and social work (CDC, 2020a; IDEA, 2004). Services provided under Part C focus on family goals and are determined through an Individual Family Service Plan (IFSP). The IFSP includes current

developmental level, family needs, strengths, specific services for the child and their family, and a plan to facilitate the transition to public school (CDC, 2019a; IDEA, 2004). Part B of IDEA ensures that school-aged children, ages 3-21, who have an eligible disability, will receive a free and appropriate education (FAPE) through the public school system (CDC, 2019a; IDEA, 2004). Services included under IDEA Part B are specially designed instruction, related services such as speech, occupational and physical therapy, assistive technology, and supplementary aids and services (CDC, 2019a; IDEA, 2004). Services for Part B are determined through an Individual Education Program (IEP). The IEP is similar to an IFSP, but the plan focuses on goals for the child rather than family and child goals (CDC, 2019a). An IEP and IFSP should include research-based practices that effectively improve development and learning outcomes for young children with developmental delays or disabilities (ECTA, n.d; IDEA 2004; Yell et al., 2020).

### **Current Prevalence and Demographic Data**

In their 41<sup>st</sup> report, The Office of Special Education and Rehabilitative Services (OCERS) reported that in the 50 states and the District of Columbia, 386,155 children received services under Part C of IDEA and 760,614 children ages three to five received services under Part B (Office of Special Education and Rehabilitative Services [OSERS], 2020). Of those children, 10.8% were eligible under the disability condition of autism (OSERS, 2020). In the report to Congress, the Office of Special Education and Rehabilitative Services found that in Texas, 26,129 children were eligible for Part C services in 2017, and 49,681 children ages three to five received services under Part B (OSERS, 2020). A report from the Texas Autism Council reported an estimated 26,129 students from birth to three that are diagnosed with ASD in Texas (Texas Autism Council, 2019). In the same report, they estimate a total of 71,951 students with the diagnosis of autism in K-12 (Texas Autism Council, 2019). Information from the Texas

Education Agency reported that 58,444 students, 12.5% of the population, have a diagnosis of autism (Texas Education Agency [TEA], 2018).

In this study, it is also important to capture the number of special education evaluators that provide services to children with disabilities. Nationally, 203,518 full-time, fully certified personnel provide related services to children under Part B of IDEA (OSERS, 2020). Of those, psychologists made up 35,461 of those providers. When determining the diagnosis of autism within the educational model, the primary evaluator responsible for making the determination is a school psychologist or Licensed Specialist in School Psychology. In Texas, psychologists who are credentialed to work in schools are called Licensed Specialists in School Psychology (LSSPs), and in other states, they are referred to as school psychologists. In 2019, Texas reported licensure for 3,522 LSSPs (Texas Department of State Health Services [DSHS], 2019a). Licensed psychologists (LP) and LPCs (licensed professional counselors) can also work in private practice to diagnose ASD. Currently, there are 4,823 LPs licensed in Texas (DSHS, 2021). As of 2019, there were 20,933 actively licensed professional counselors (LPCs) in Texas (DSHS, 2019b).

### **Child Find**

Child find is an ongoing affirmative process of bringing public awareness and coordinating with primary sources, agencies and screening procedures to locate, identify and evaluate all children with disabilities from birth to age 21 who may require early intervention or special education services (IDEA, 2004; TEA, 2020). The process involves locating all children with a disability, including finding children before school age, those enrolled in public schools advancing grade to grade, and children who are parentally placed in private school, homeschool, or virtual school (IDEA, 2004; TEA 2020). This process also includes homeless or highly mobile populations, including

migrant children and children in foster care, wards of the state, involved in the criminal justice system, or who reside in nursing homes (IDEA, 2004; TEA, 2020).

The responsibilities of the local education agency (LEA) when it comes to child find are to develop written policies and operating procedures, engage in awareness activities, and partner with primary referral sources (IDEA, 2004; TEA, 2020). LEAs must conduct school-wide screenings, ensure appropriate and timely evaluation referrals, coordinate with other agencies, including Early Childhood Intervention (ECI). LEAs must maintain accurate data, notify parents annually of the Right to Information Statement and provide training and professional development to all staff (IDEA, 2004; TEA, 2020).

A comprehensive review of case law by Zirkel (2017) took 91 Child Find cases from the mid-1990s to the end of 2016, including those with reasonable suspicion and reasonable period of time triggers. In order to fulfill the requirements of child find, districts need to request an evaluation for students once they have reasonable suspicion to believe a child has a disability, and consent must be obtained within a reasonable amount of time (Enis et al., 2017). Zirkel (2017) found an upward trend in court decisions involving child find, with most of the rulings specific to reasonable suspicion and 60% of the cases' rulings in favor of school districts. The pro-district trend was less apparent in reasonable period rulings. In 2020, Zirkel completed an updated case review of Child Find cases to determine if previously found trends remained consistent. Consistent with previous findings, cases continue to trend upwards and favor districts in reasonable suspicion rulings. Recommendations for practice for school psychologists regarding Child Find are reminders to continue to differentiate professional norms from minimal legal standards to ensure rapid and responsive action. School psychologists are also

recommended to differentiate legal objectivity from professional advocacy, with legal literacy most important (Zirkel, 2020).

Shapiro and Derrington (2004) completed a review of Hawaii's early intervention Child Find to examine referral and enrollment access and equity within subpopulations. Results indicated that immigrant and low-income households were both able to access services. Access by military families appeared less equitable. Conflicting reports for access were obtained from parents who spoke little English. Families with uninsured children had the least equitable access to early intervention. This review made recommendations to improve Child Find practices, including expanding outreach to uninsured and military families.

### **Interventions for ASD**

Common treatments for autism can include communication and behavior therapies, educational therapies, family therapies, and sometimes medication. Possible intervention approaches for ASD could include applied behavior analysis (ABA), assistive technology, social skills training, speech therapy, and occupational therapy (CDC, 2019b). Medication cannot cure core autism symptomatology but can help control symptoms, such as hyperactivity (Mayo Clinic, 2018). Some parents choose to try specific dietary treatments to address autism symptomatology. However, there is little evidence to support the effectiveness of dietary treatments though some parents reported it to make a difference in how their child feels and acts (CDC, 2019b). A National Professional Development Center (NPDC) Review of Autism Spectrum Disorders from 2014 outlined 27 evidence-based practices for children with autism (Wong et al., 2014). A comprehensive search strategy was used to access data by collaborating with research librarians at the UNC Health Science Library for this review. Coverage of literature included peer-reviewed journal articles published between 1990 and the end of 2011. A

national panel of 159 reviewers were recruited and trained to evaluate journal articles. From an initial set of 29,105 articles, NPDC investigators identified 456 articles judged methodologically acceptable, which were then sorted into practices. Using this process, they identified 27 focused interventions that meet the criteria as being evidence-based (Wong et al., 2014).

These interventions are antecedent-based intervention (ABI), naturalistic interventions (NI), self-management (SM), cognitive-behavioral intervention (CBI), parent-implemented interventions (PII), social narratives (SN), differential reinforcement (DR), peer-mediated instruction and intervention (PMII), social skills training (SST), discrete trial training (DTT), picture exchange communication system (PECS), structured playgroups (SPG), exercise (ECE), pivotal response training (PRT), task analysis (TA), extinction (EXT), prompting (PP), technology-aided instruction and intervention (TAII), functional behavior assessment (FBA), reinforcement (R+), time delay (TD), functional communication training (FCT), response interruption/redirection (RIR), video modeling (VM), modeling (MD), scripting (SC) and visual supports (VS) (Wong et al., 2014).

### **Barriers**

Determining the barriers that prevent a family from accessing needed services can help service providers better tailor their programs and services to increase access for families. A study by Heath et al. (2018) examined the participation of 136 parents in a school-based intervention program found that one-third of the parents did not attend the program. Higher SES and higher educational attainment were found to have a positive impact on participation. The families who need intervention most seem to be the most likely not to attend the programs. Less-educated parents and families of lower SES were found to have a reduced capacity to manage the issues that would impact program attendance. For example, fewer transportation options, difficulties predicting work



demands, reduced social support, and poorer access to the ‘catch up’ workshops conducted at centralized locations (Heath et al., 2018). Based on existing literature, the following sections address the most commonly reported barriers. They include the age of diagnosis, gender, socioeconomic status, cultural and ethnic barriers, parental barriers, and medical and educational barriers.

### **Age of Diagnosis**

In the United States, there is a persistent gap between the percentage of children eligible to receive early childhood services and the percentage of children who use the services (Gennetian et al., 2016). Children and families with ASD report experiencing difficulties with various spheres of life (e.g., mental health, finances, employment, social relationships) and have difficulty accessing diagnostic and intervention services for their children with ASD (Brookman-Frazwee et al., 2012). Many children with developmental and behavioral concerns are not identified as early as possible, resulting in a delay in accessing services in their social and educational settings (CDC, 2020a; Clark et al., 2018; Suma et al., 2016). This delay in diagnosis can result in significant delays with missed opportunities for intervention (CDC, 2020a; Clark et al., 2018; Suma et al., 2016).

### **Gender**

One barrier to accessing diagnostic and intervention services for children is gender. Maenner et al. (2020) examined the prevalence of ASD among eight-year-olds and found that boys are four times more likely than girls to be diagnosed with ASD. When examining factors related to autism screening, Matheis and Matson (2015) found that girls are less likely to be screened for autism than males. The disparity in diagnosis between males and females is thought to be related to autism being traditionally considered a predominately male disorder, with most research being conducted on males resulting in a biased understanding of the autism spectrum (Kopp & Gillberg, 1992;

Milner et al., 2019). Research has consistently revealed that females are often delayed in receiving an autism diagnosis (Bargiela et al., 2016; Gould & Ashton-Smith, 2011; Navot et al., 2017). In exploring female experiences with ASD, Milner et al. (2019) found that females with ASD reported more pressure to fit into the social norm and reported wanting friendships but having difficulty doing so. They also tend to camouflage symptoms meaning they disguise autistic traits to better fit in with peers. Girls with ASD learn and mimic acceptable social behavior, resulting in missed and delayed diagnosis of ASD (Milner et al., 2019). Females with autism often report being more motivated to seek out friendships and interactions with others and also engage in “masking.” Masking is a term used to describe behaviors of females on the autism spectrum relating to learning and mimicking socially acceptable behaviors due to societal pressures. (Bargiela et al., 2016). Bargiela et al. (2016) examined the experiences of 14 women, ranging from aged 22 to 30 years of age, who were diagnosed with autism in late adolescence or adulthood. The participants reported shared experiences of pretending to be normal, missed or delayed diagnoses based on perceived gender factors, and conflicts with their gender identity. They frequently shared incidents of sexual abuse related to perceived vulnerabilities due to being an undiagnosed female with ASD.

Navot et al. (2017) examined maternal experiences associated with raising girls with ASD. Mothers of girls with ASD often felt excluded from both the general neurotypical population and ASD populations due to its male dominance. Mothers reported experiencing delays in diagnosis and perceived skepticism of their concerns when seeking support or information. Mothers also reported difficulties finding general information about ASD in girls. They also reported difficulties navigating puberty and the high social demands during adolescence. Of most importance, mothers also expressed

concerns about their daughters' vulnerability in social relationships and shared their worries about their daughter's ability to function in the future (Navot et al., 2017).

### **Socioeconomic Status Barriers**

Another barrier to accessing services for children with ASD is a family's socioeconomic status (SES). Pickard and Ingersoll (2016) investigated how SES influenced parents' ability to access services for children on the autism spectrum. Upon interviewing 244 parents, they found that both high and low SES families are aware of basic needs related to their child's ASD. However, parents from a lower SES reported needing more information about available services, a greater need for in-home services such as respite care and parent training. Low SES families often reported more structural barriers to services such as work schedules, service hours, and limited after-work hours. In this same study, families from a higher SES reported needing higher quality services such as social skills groups. They also reported difficulties paying higher out-of-pocket costs for services than families who qualified for free or reduced-priced services. Both parents of high and low SES reported needing a larger quantity of their current services and wanting more hours during the day when those services are available (Pickard & Ingersoll, 2016).

In a similar study that analyzed the effect of poverty and caregiver education on perceived needs and access to health services for children with special health needs, Porterfield & McBride (2007) found that less-educated and lower-income parents were less likely to say that their child needed specialized health services. Additionally, lower-income families were more likely to say their child had severe functional impairments but less likely to report needing specialized health services. This may be due to the higher cost of services that can be a barrier for some families accessing services. In contrast, higher-income families had a higher probability of accessing specialized services and

were more likely to have coverage from insurance. Public and private insurance were reported to be equally effective in accessing specialty services from physicians and getting prescription medications. However, both public and private insurance companies were equally ineffective at providing access to therapy services. Parents who had been uninsured for at least one month during the prior year were also less likely to access services (Porterfield & McBride, 2007).

Kerns et al. (2017) examined the association between adverse childhood experiences and ASD. In this study, the adverse childhood experiences focused on were poverty, intellectual disability, and other mental health conditions. They found that children with ASD experience more adverse experiences than typically developing children. This difference is especially evident in lower-income families making these families particularly vulnerable due to their limited financial resources and the associated social, emotional, and financial challenges associated with caring for a child with ASD. The challenges often result in strain or disruption in the family (Kerns et al., 2017).

King and Bearman (2011) conducted a study to explore the impact of SES on autism prevalence in California by examining data sets on birth cohorts from 1992 to 2000. The researchers found the impact of the SES related to the diagnosis of ASD lessened over time but persisted in families with fewer economic resources. Essentially, as time and practices progressed, children, who would have been less likely to be diagnosed in previous cohorts, became more likely to be diagnosed. Yet, consistently over the timeframe for the archival data analysis, higher SES families with higher parent education and economic resources were associated with a higher likelihood of diagnosis. The economic effect remained consistent for children born into families with fewer economic resources (King & Bearman, 2011). When comparing case severity, initially, higher SES families were more associated with less severely disordered cases. The

impact of SES was less apparent for more severe cases but was still present. This discrepancy was attributed to higher SES families having access to diagnostic resources and knowledge of the disability condition of ASD. The authors postulated, this effect has lessened as knowledge of disabilities is common and available in areas with fewer economic resources (King & Bearman, 2011).

### **Cultural and Ethnic Barriers**

When addressing barriers to accessing services for children with autism, it is essential to examine cultural differences and how that impacts a family's willingness and ability to seek out services for their child with ASD. Mental health stigma, the parenting approach, perceptions of developmental milestones, and help-seeking are influenced by culture (Zuckerman et al., 2017).

According to the research, Black and Latinx children have lower rates of autism than White children (Maenner et al., 2020). Further, recent research shows that the gap in prevalence rates between diagnosis of Black and Latinx is decreasing but remains (Maenner et al., 2020).

The following sections synthesize the research related to specific cultural and ethnic barriers of guilt and stigma, lack of autism knowledge, limited family support, and difficulties navigating the educational system.

#### ***Guilt and Stigma***

In reviewing literature for culturally diverse populations, parents often reported guilt and shame related to having a child with autism (Lobar, 2018; Lopez et al., 2018; Dababnah et al., 2014). Lopez et al. (2018) examined maternal reaction to the diagnosis of ASD in 44 Latinx mothers and 52 White mothers. Latinx mothers reported higher feelings of guilt related to their child's diagnosis. White mothers reported experiencing relief from guilt after their child was diagnosed with ASD (Lopez et al., 2018). Lobar

(2018) asked 14 Hispanic caregivers about their perceptions and adjustment to the autism diagnosis. Parents feared stigma and worried about how the community would perceive their child. Parents reported feeling less skilled in knowing how to interact with their children. (Lobar, 2014). Similarly, Lopez et al. (2018) found that families may experience isolation from their extended families and their communities due to having a child with autism. Latinx mothers may be blamed for their child's difficulties by their extended families. A child's difficulties were often attributed to the mother's lack of parenting skills or spoiling the child (Lopez et al., 2018).

Similar concerns with stigma and shame related to an ASD diagnosis were found within the Black community. Dababnah et al. (2018) explored the perspectives of 22 Black female caregivers of children with ASD regarding screening and referrals processes. When asked about reasons for delayed services, parents reported experiencing denial of the overt symptomatology and the fear of labeling their child with a disability. Caregivers experienced denial, stigma, and shame of ASD in the Black community as possible factors for delays in following up on referrals for services (Dababnah et al., 2018).

Zheng et al. (2016) gathered the experiences of six Chinese families accessing early intervention services for their children in China. As was found in other cultures, families also identified the stigma and rejection of their children with disabilities as barriers to pursuing identification and access to services. Zheng et al. (2016) found that while some progress has been made with disability acceptance and early intervention in the last 30 years, many families still reported fears of rejection by peers and teachers due to their children having a disability. Parents want their children to learn basic care skills, limit observable disability symptoms, and want their children to live in normal society (Zheng et al., 2016). Kang-Yi et al. (2018) examined the community-level cultural

beliefs of a Korean American community in New York and how they affect the professional and family outcomes for children with developmental delays and autism. Community members reported that the prevailing community attitudes towards autism and developmental disorders are discomfort, discrimination, and stigma. These beliefs then impact professionals' and families' understanding and care for children with autism and developmental disorders. (Kang-Yi et al., 2018).

### ***Lack of Autism Knowledge***

Durkin et al. (2010) found that parent education and income influence access to care and diagnostic services for children with ASD. Magaña et al. (2013) examined access to diagnostic and treatment services for Latinx children by comparing the services of 48 Latinx and 56 non-Latinx children. Results showed that Latinx children are diagnosed almost one year later than white children. They had higher unmet service needs and received fewer services. The factors accounting for this disparity are lack of knowledge about autism and maternal education level. Both White and Latinx mothers reported high levels of misinformation regarding autism. However, Latinx mothers reported that aside from lacking knowledge of autism in general, they were also not aware of the common characteristics and problems associated with autism. Similarly, Lopez et al. (2018) found that when reflecting on their evaluation experiences, White mothers expressed disappointment with the evaluation process that Latinx mothers did not report. The researchers concluded this difference is a result of Latinx families being less informed about the diagnostic process. White mothers tended to be already looking for a diagnosis, where Latinx mothers were more surprised by the diagnosis and reported knowing less about ASD. A lack of knowledge about autism results in Latinx families being more likely to experience mismatched treatments, limitations in their family functioning, and a lower quality of life (Lopez, 2014).

A lack of knowledge related to ASD was also reported within the African American communities. Pearson and Meadan (2018) examined the perceived factors that impede and facilitate early access and diagnosis among African American parents of children with ASD. The biggest barriers to obtaining an autism diagnosis were denial, lack of knowledge of ASD, and cultural differences between families and professionals. The biggest facilitators for gaining a diagnosis were parent knowledge of ASD, healthcare professionals' knowledge of ASD, high SES, and community networks. When assessing access to services, the additional barriers of not knowing how to advocate for their child, time/work commitments, and a lack of community resources were reported. Facilitators to services access for African American families were parent involvement, extended family support, and trust in the professionals (Pearson & Meadan, 2018). In their study, Dababnah et al. (2018) also found that lack of autism knowledge contributed to the later diagnosis of ASD among Black children. This delay results in Black children receiving less early intervention than White children (Dababnah et al., 2018).

Asian families also reported parent autism knowledge impacts the diagnosis and onset of services for children. Zheng et al. (2016) found that families in China lacked knowledge of disabilities and often had outdated views of disabilities as an illness that can be cured or caused by parental experiences. Similar to other cultures and ethnicities, there is a level of discomfort with autism. A lack of understanding of autism and needs related to care was also reported in Korean American communities (Kang-Yi et al., 2018). Consistent with prior research findings, beliefs about the cause and treatment of ASD were influenced by knowledge of the condition. Grinker et al. (2015) worked with Korean communities to culturally adapt and translate outreach materials to better meet the communities' needs. Misconceptions related to ASD and its etiology in Korean communities were prevalent. Low parent intelligence, poor parents, a low-income family



environment during pregnancy, and a lack of love from caregivers were thought to be causes of ASD (Grinker et al., 2015).

### ***Extended Family Support***

The lack of support from extended family was also another commonly reported barrier for children with ASD. Latinx families reported that extended families took longer to accept the autism diagnosis, thus delaying the parent's ability to process the diagnosis (Lopez et al., 2018). Latinx extended families often downplayed symptomatology based on physical appearance and often pursued cures for the diagnosis through Faith Healers and other spiritual means (Lopez et al., 2018). Within Black families, family members' and friends' knowledge and mindset towards autism were also potential barriers to support and services. (Dababnah et al., 2018).

### ***Difficulties Navigating the Educational System***

Families that are culturally and linguistically diverse (CLD) also experience barriers when advocating for their children within the educational system (Jung, 2011). Jung (2011) reviewed current research on individualized education programs (IEPs) and barriers for linguistically and culturally diverse parents. Overall, Jung (2011) found that families felt that their opinions were not valued, and there was a lack of recognition of cultural diversity. School practices can be perceived as insensitive to families' values and may act with cultural assumptions instead of the individual circumstances (Jung, 2011). Cobb (2014) also reviewed the literature on culturally and linguistically diverse parental involvement in special education in Canada and the United States. The analysis of 20 articles published in journals between 2000 and 2010 looked for patterns involving parent involvement specifically with culturally and linguistically diverse (CLD) families. School perceptions of CLD families often negatively influence parental inclusion, and parents are often judged and evaluated outside of the context of their cultural norms.

CLD families report having difficulty navigating the verbal and written exchanges needed to successfully participate in the special education process. CLD parents can face numerous barriers related to social-cultural capital, which can be attributable to school professionals and systemic forces connected to people, perceptions, and systems.

In another study, Kozleski et al. (2008) examines culturally and linguistically diverse families and service providers within the educational system in the United States and South Africa. Families across both countries were also more willing to participate when they felt welcomed and accepted by educators. Professionals often reported having more boundaries in relationships than families. Families reported challenges navigating the specific terminology needed to advocate for their child in special education (Kozleski et al., 2008).

### **Parental Barriers**

As noted in many of the studies shared in the previous sections, parents can also be barriers to access for students with ASD. Parents from all backgrounds report needing disability-specific information, services availability, child-specific strategies, and information on general child development (Jung, 2010; Shannon, 2004).

In a study by Jimenez et al. (2012) that examined parental barriers to evaluation for early intervention services, parents often reported communication problems with their physician as barriers to accessing services. Parents reported not understanding the referral process and misinterpreting the pediatrician's reassurance, causing them to lessen their child's developmental concerns. Parents also reported that they knew their child best, and it should be up to them if their child receives services. Parents also reported concerns that evaluations did not always accurately capture their child's development. Parents who disagreed with the assessment or denied issues were less likely to access services following the evaluation. Some families preferred to see if issues resolved themselves

before seeking intervention. Families ambivalent towards the process were less likely to overcome practical obstacles to access services, but highly motivated families were more likely to complete the evaluation process and access services (Jimenez et al., 2012).

Similarly, Shannon (2004) found that families needed to be highly motivated and persistent to obtain services for their children. Parents who are not highly motivated experienced delays in intervention and services for their children. When considering participation in services, families often cannot place the needs of one child over the needs of their other children. Families also have to consider daycare issues, transportation issues, financial concerns, and work conflicts when deciding to participate in therapy (Shannon, 2004).

### ***Maternal and Paternal Support Needs***

The paternal perspective and experience when diagnosing and accessing services for children with autism are not well represented in research (Braunstein et al., 2013; Potter, 2017; Papageorgiou & Kalyva, 2010). Studies involving ASD are predominately conducted with mothers where they outnumber the representation of fathers 8:1 (Potter, 2017). Papageorgiou & Kalyva's (2010) examined parents of children with ASD's self-reported needs and expectations of support groups. Mothers and fathers reported having different support needs, but often the focus is on the mother's perspective and experience and less on what the father is experiencing. Braunstein et al. (2013) also addressed father participation when investigating eligibility considerations for autism spectrum disorders. They found that fathers' experiences were not as well represented in research, making it difficult for service providers to appropriately and accurately support fathers during the diagnostic process. Potter (2017) investigated the perspectives of 184 fathers related to an autism diagnosis by having fathers respond to open ended questions regarding the diagnostic process. According to the results, fathers often reported feeling not

appropriately included in the evaluation and unsupported (Potter, 2017). Fathers reported dissatisfaction with the delivery of diagnostic information, reported it was brief, emphasized the negative, and lacked sensitivity. Fathers reported that they experienced strong emotional reactions to the diagnosis and commented that the information provided at diagnosis and after was inadequate in answering their questions. The intensity of paternal response to the autism diagnosis and the lack of gender-specific support results in fathers being less able to cope with family challenges and impacts all familial relationships and functioning (Potter, 2017).

### ***Parent Participation***

Parent participation is described in the literature as parents fully participating in an educational partnership with providers and active involvement in all situations (Pretis, 2011). Parent participation can be impacted by both systemic as well as individual barriers. Staff quality, workload, turnover, and the lack of cultural and linguistic sensitivity in delivering services can reduce parent participation in programs (Gennetian et al., 2016). Further, individual barriers such as domestic violence, substance abuse, depression, and finding care for a child with developmental needs can also reduce parent participation in programming (Gennetian et al., 2016). In order to increase participation in early childhood services, parents need more individualized services, brief parent sessions, and access to programs via the workplace (Lee et al., 2014). Parents also reported wanting to have more choices for the professionals who work with their child and more choice in the services a child is eligible to receive (Pretis, 2011).

### ***Financial Burden, Insurance Companies & Cost of Services***

The hurdles put in place by insurance companies for parents seeking support and the associated cost of services can frequently be a barrier for families seeking to access services for their child with ASD (Shannon, 2004, Gray, 2002). Shannon (2004) looked

at barriers to accessing family-centered services for children with developmental delays from the perspectives of families. Families reported that they are not involved in the decision-making process of insurance companies. The number of billable services is being reduced, which increases out-of-pocket costs and limits access. Limitations on the number of covered sessions and limits on funding reduce student access and minimize the effectiveness of interventions. Parents reported feeling frustrated dealing with insurance companies and feeling like they have to fight for needed services and coverage for their children with disabilities (Shannon, 2004). Parents are often limited in their ability to have full-time employment when accessing services for their children (Gray, 2002). Often therapy occurs during the workday, making it difficult for parents to work and access therapies and supports. Parents reported that paying for services, insufficient free public resources, and high out-of-pocket costs for private services are barriers to gaining needed intervention for children with ASD (Sharpe & Baker, 2007). Increased participation in intervention programs was reported when families were supported through monetary funding and understanding of the families' needs (Carr & Lord, 2016).

### **Physicians**

A key determinant in the early diagnosis of an autism spectrum disorder is the physician. Conversely, physicians can also be a barrier to service access for parents if they cannot make an accurate diagnosis or referral for additional evaluation or services (Self et al., 2015). Self et al. (2015) sought to identify screening practices of 481 family physicians and pediatricians following the American Academy of Pediatrics (AAP) guidelines for ASD. Only 17% of the respondents routinely screened for ASD using the AAP guidelines. 41% of the respondents screened for ASD but did not follow guidelines. Pediatricians were more likely to screen for ASD than family physicians. Physicians reported they lack time and training in ASD symptomatology. This limited familiarity

with ASD contributed to their reluctance to diagnose ASD at three years of age (Self et al., 2015).

When looking for barriers to access from the perspectives of families and self-providers, both reported the physician as a potential barrier to family-centered services (Shannon, 2004). Several parents reported that they disagreed with the physician and were subsequently labeled noncompliant. One professional in the study reported concerns with physicians not talking to or listening to families. Physicians may not have the knowledge to address a parent's specific concerns and were reported to overutilize medical jargon frequently. A parent also supported this perception reporting that she felt unable to use the same language as the doctor and did not feel she could voice her concerns (Shannon, 2004). Physicians will often take the "wait and see" approach to developmental delays instead of acting on them quickly, leaving some children without services for months or even years (Shannon, 2004).

### **Provider Bias**

Another barrier to accessing diagnostic and intervention services for children with ASD is the growing research on provider bias and its impact on the experiences of children in families when they seek supports and services. Socioeconomic status was found to play a role in the perception of service providers towards families and their participation (Shannon, 2004). In his study, Shannon (2004) also gathered service providers' perspectives to determine barriers to accessing family-centered services for children with developmental delays. For middle-income families, providers perceived a lack of parent participation in early intervention services because families equated services to welfare (Shannon, 2004). In contrast, services providers perceived lower-income families who were not participating in the process were perceived by providers as lazy, uneducated, or substance abusers (Shannon, 2004). Ethnic incongruences between

racially diverse groups and White practitioners also impact the diagnostic process (Travers et al., 2013). Black and Latinx families are more likely to report that their provider did not spend enough time with their child and perceived providers to be insensitive to customs and values (Magaña et al., 2012). Therefore, it is critical to highlight the research that addresses the role practitioner biases involving cultural and Ethnic barriers play in outcomes for children and families.

Zuckerman et al. (2013) examined practices for identifying ASD in Latinx children by 267 primary care physicians (PCP). Results of the study found that many PCPs (81%) offer some form of developmental screening. However, only 29% offered the screening in Spanish as outlined in the American Academy of Pediatrics (AAP) guidelines. Only 10% of physicians offered both Spanish ASD screening and ASD general developmental screening per AAP guidelines. This study went further to compare the perceptions of PCPs of Latinx parents compared to White parents. PCPs reported that Latinx parents were less knowledgeable about ASD. Providers reportedly had more difficulty assessing risk for ASD in Latinx children with a primary family language of Spanish than they had with White English-speaking children. PCPs also reported more difficulty assessing ASD risk for Latinx children with Spanish primary family language. The most frequent barrier to ASD identification in Latinx children was limited access to developmental specialists, primary care physicians, and the language differences between providers and families (Zuckerman et al., 2013). Latinx families tend to live in areas with fewer pediatricians and services and are less likely to get an early diagnosis (Zuckerman et al., 2017).

In their study, Pearson and Meadan (2018) investigated the parent perceptions of their diagnostic and service experiences for African American children. African American families report that healthcare providers were non-responsive to their

developmental concerns. Dababnah et al. (2018) similarly found that many Black parents reported that their initial concerns about their child's development were not listened to, which delayed their child's diagnosis. Parents felt that assumptions were made about their children and families based on the family's race, knowledge, and income (Dababnah et al., 2018).

### ***Educators***

While many educators are skilled in pedagogy and have valuable classroom experiences, they can also serve as barriers to access for children with ASD. Sanchez et al. (2019) examined the perspective of 86 future education professionals on barriers to student learning and participation in inclusive settings. The most commonly reported barriers were physical barriers, lack of teacher training to work with diverse populations, limited ability to use existing resources, and a lack of organizational strategies to facilitate an inclusive environment (Sanchez et al., 2019). Perspective education professionals reported that they lacked the training to work with all students and their diverse needs and lacked the resources to support students equally. Future education professionals also reported a lack of strategies and support for students to support an inclusive environment. Often, reporting that the responsibility of student support fell back on the specialist working with the child as opposed to the classroom teacher (Sanchez et al., 2019).

### **Theoretical Framework**

Research shows the importance of understanding the experiences of families in accessing services for children with ASD. These experiences can be gathered both from the parent perspective and the evaluator perspective. According to Bronfenbrenner's ecological view (1988), it is crucial to understand the needs of a child and the environment they are in, and how those systems interact with each other to impact



development. At the core of Bronfenbrenner's ecological model is the understanding that a child's biological and psychological makeup is impacted and changed by their immediate social and physical environments and the related interactions among the systems in their environment (Bukatko & Daehler, 1998).

Koller et al. (2020) developed the ecological engagement methodology (EEM) to operationalize Bronfenbrenner's bioecological theory. EEM was reported to be an effective way to apply Bronfenbrenner's model in context and yield ecologically valid high-quality data that is relevant to stakeholders. The EEM model is built off of the bioecological theory combining new and old elements to capture the complexity of human development. The model is an outgrowth of the interrelated concepts of process, person, context, and time. Process refers to the dynamic exchanges between the environment and the developing person. Person refers to the development of characteristics in an individual. Context refers to the social and physical environments that shape a person's daily experiences. Time refers to the longitudinal nature of an individual's development, routine, and history. The core of the EEM model is the engagement process itself. Within this methodology, there are five elements to the engagement process. The five elements are forging a connection between the researcher-participant, creating a field diary, data collection, research team supervision, and prioritizing the relationships among participants, institutions, and researchers. Using this perspective when gathering evaluator and parent perspectives allows for a better understanding of the needs of parents and children with ASD and meaningful improvement in support services for children with ASD.

### **Conclusion**

The research reviewed in this chapter consistently states the importance of early diagnosis and intervention for children with ASD in improving child outcomes (Dawson,

2008; Duncan & Magnuson, 2013; Guralnick, 2011; Suma et al., 2016). Despite all the research supporting early intervention, the gap persists between eligible families and families who participate in services (Gennetian et al., 2016). This is why it is critical to capture parents' and evaluators' experiences accessing services to improve access, reduce barriers, and provide appropriate and meaningful support to children and families.

## CHAPTER III: METHODOLOGY

This qualitative study examined parent and special education evaluators' experiences accessing services for children with autism spectrum disorders (ASD) to gain insight into additionally needed services for children with ASD. To provide demographic information, participants completed a survey, and interviews were conducted from a purposive sample of parents of children with autism and special education evaluators in the southeastern part of Texas. An inductive coding process was used to analyze the qualitative data. This chapter presents an overview of the research problem, purpose and questions, research design, population and sampling selection, data collection procedures, data analysis methods, privacy, ethical considerations, and the research design limitations for this study.

### **Overview of Research Problem**

Access to early childhood intervention and services is vital for children with ASD. The earlier appropriate intervention is determined and initiated, the better the prognosis in the future (Dawson, 2008). Research has shown across settings that early childhood services positively impact child development, and early intervention can curb the effects of the full presentation of the symptomology of ASD (Dawson, 2008; Muschkin et al., 2015). Therefore, children must have access to interventions as early as possible to meet their developmental potential. In order to do this, barriers to accessing services must be reduced, and needed services must be available to all families who need them. This research can be used to identify specific barriers to interventions, inform efforts to reduce barriers, and increase access to early interventions for children with ASD.

### **Research Purpose**

The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD in order to gain insight into additionally needed services for children with ASD.

### **Research Questions**

This study addresses the following research questions:

1. What are parent experiences accessing services for children on the autism spectrum?
2. What are special education evaluators' experiences working with children to access services for children on the autism spectrum?
3. What additional services and supports do parents feel would benefit their children on the autism spectrum?
4. What additional services and supports do special education evaluators feel would benefit children on the autism spectrum?

### **Research Design**

In this study, a multiple case study research design was employed. A case study was appropriate for this study due to the need to capture the individualized experiences of parents and evaluators (Yazan, 2015). Qualitative data was gathered through interviews conducted over the phone to gain a personal perspective on parent and evaluator experiences accessing ASD services and what additional services are needed. Qualitative data were analyzed using an inductive coding process.

### **Participant Selection**

Participants for interviews were self-selected from a convenience sample of parents of children with ASD and special education evaluators in southeastern Texas. Information regarding the study was sent in an email to community contacts to provide to parents of children diagnosed with ASD. Parents who chose to participate completed a

brief survey to provide demographic information and contact information. Those who provided contact information were contacted for an interview. An email was also sent to special education evaluator contacts in Texas, and those who chose to give demographic information and provided contact information were contacted for an interview.

Parents or examiners agreed to participate in individual interviews. Data were gathered from four parent interviews and five examiner interviews. All parent participants self-reported a diagnosis of ASD for their child. All examiners reported that they currently participate in evaluations for children with ASD within their professional setting. A fifth parent was recruited for the study but dropped out due to scheduling conflicts and frequent reschedules. All parents and examiners live in Texas and access services in Texas.

### **Data Collection**

Before any data collection occurred, the researcher obtained approval from the University of Houston-Clear Lake's Committee for Protection of Human Subjects (CPHS).

The researcher distributed the survey through Qualtrics. The survey started by asking the parent if their child has been diagnosed with ASD, and if their child has not been diagnosed, the survey ended. Parents who felt their child may be on the spectrum, but the child had not been diagnosed, were not included. The survey continued for parents who indicated their child had been diagnosed with ASD, and demographic information was then collected. The demographic information collected included the child's current age, age of ASD diagnosis, household income, and parent education level. At the end of the survey, parents were given the option of providing their contact information. Providing contact information gave the researcher consent to contact the parent for an interview.

In order to obtain evaluator experiences, evaluators who chose to participate completed a brief survey that asked work experience questions such as occupation, years of experience, and experience working with students with ASD. Consent was obtained from evaluators when they began the survey. Evaluators were also be asked to provide contact information if they wished to participate in an interview. Evaluators that provided contact information were contacted for interviews.

### **Interviews**

Parent and special education evaluator interviews were used to better understand the personal experiences related to service barriers and needed services for children with ASD. Parents and evaluators who provided contact information on the survey were contacted and scheduled for an interview. Informed consent was obtained before the interviews were conducted. A semi-structured interview format was used for both parents and evaluators. Parent questions included the background of the child, information about the diagnostic process, parent-reported barriers, positive experiences, known resources, and needed resources for children with ASD. Evaluator questions included personal experiences working with children with ASD, observed barriers, experiences in helping families access services, and needed resources for children with ASD. Interviews were conducted on the phone or through a virtual platform such as Zoom. The interviews were recorded and transcribed and took approximately 30 minutes to complete. Data was stored on a password-protected USB storage device.

### **Data Analysis**

Qualitative data from the parent and evaluator interviews were analyzed using an inductive approach to answer the research questions. All of the data collected were entered into NVivo to facilitate the organization and categorizing of data. The researcher then analyzed the data by coding and categorizing to determine salient themes.

## **Validity**

Several techniques were utilized to increase the validity of this study, including triangulation and peer debriefing. Triangulation of ideas occurred through peer editing and referencing existing literature. Data was gathered from multiple data sources and compared across participants. Peer review allowed the researcher to obtain feedback from peers to validate the appropriate analysis of concepts, recurring themes, and perceptions. Peer debriefing was also conducted through conversations with research colleagues to ensure objectivity and obtain feedback on the validity of data analysis.

## **Privacy and Ethical Considerations**

Before collecting any data, the researcher gained approval from the UHCL's CPHS. At all times, the data was secured in the researcher's computer within a password-protected file. The researcher will maintain the data for five years, the required time set forth by CPHS guidelines. Once the deadline has passed, the files will be destroyed. Before completing the surveys, participants and evaluators viewed a cover letter indicating the purpose of the study. The letter included that participation was entirely voluntary, that identities would be confidential, and that pseudonyms would be used. Consent was implied upon completing the survey. Before conducting interviews, all participants were required to sign an additional informed consent acknowledging their voluntary participation and reinforcing confidentiality. Interviews were conducted over the phone or in a virtual format like Zoom.

## CHAPTER IV:

### RESULTS

The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD and to gain insight into additionally needed services for children with ASD. Interviews with parents and evaluators determined factors that provided access or served as barriers to obtaining services for children with ASD. The researcher examined four parent and five evaluator experiences as told through their perspectives. The study explored which factors inhibit student participation in services while determining which factors contributed to service access. Patterns and themes were extracted from the information shared by participants describing their experiences. The research questions guiding this study were what are parent and evaluator experiences accessing services for children on the autism spectrum and what are additionally needed services that parents and evaluators feel would benefit children on the autism spectrum. This chapter begins by presenting a description of the demographic characteristics of the participants, portraits of participants, and experiences, followed by the data analysis.

#### **Description of the Participants**

After soliciting participants through community contacts, parents and examiners agreed to participate in individual interviews. Data were gathered from four parent interviews and five examiner interviews. All parent participants self-reported a diagnosis of ASD for their child. All examiners reported that they currently participate in evaluations for children with ASD within their professional setting. A fifth parent was recruited for the study but dropped out due to scheduling conflicts and frequent reschedules. All parents and examiners live in Texas and access services in Texas. For confidentiality, the researcher has used pseudonyms to protect names and other



identifiable information. Table 1 provides parent participants’ demographic data, including relationship to the child, age of child’s ASD diagnosis, racial identity, median household income, and the highest level of education. Table 2 provides evaluator demographic information, including racial identity, years of experience, and practice setting.

Table 4.1:

*Demographic Data of Research Participants*

Participant	Relationship to Child	Age of diagnosis	Racial identity	Child’s Gender	Median Household Income	Highest Level of Education
Lisa	Mother	2	Black/African American	Male	90,000-99,000	Professional Degree
Catherine	Mother	2	White	Female	Over 150,000	4-Year Degree
Jessica	Mother	2	White	Male	Over 150,000	Professional Degree
Robert	Father	3	White	Male	40,000-49,000	High School Graduate

Table 4.2:

*Demographic Data of Evaluator Research Participants*

Participant	Racial Identity	Years of Experience	Practice Setting
Alice	White	9	Public School
Lyn	White	15	Private Practice
Jane	White	15	Public School
Sandra	White	12	Public School
Jenny	White	20+	Public School

## **Portrait of the Participants and Experiences**

The following section gives a portrait of each participant and their experiences accessing services for children with ASD. Narrative portraits have been found to help contextualize research findings into a broader social narrative without losing the unique qualities of the research encounter (Rodríguez-Dorans & Jacobs, 2020). Parent portraits will include their developmental concerns, evaluation process, accessed services, and experiences accessing those services. Evaluator portraits will include an overview of evaluation practices, family observations, and common service recommendations.

### **Parent Participants**

#### **Lisa**

Lisa has a son with ASD. Lisa's family immigrated from Nigeria in 2011. She reported that before moving to the United States, she did not have any developmental concerns for her child and reported that she did not know the symptoms of autism. Lisa first began monitoring her child's development after seeing a segment on a television news program on developmental milestones in children. After seeing the program, Lisa said she told herself, "Okay, you know what, I'm going to observe him." Based on her observations, she considered taking her son to a developmental pediatrician but decided against it "because then I didn't think there was anything wrong .... just thought maybe kids when they don't see other kids around, probably, maybe it could be one of the reasons why he [regressed in] some of the milestones." When visiting family in another state, a family member who is a physician encouraged her to seek a developmental screening. Based on the screening, Lisa was told her son had autism. She reported that her son was around two years of age when he was diagnosed with ASD. Upon receiving the information, Lisa described her reaction:

I said. Autism. Okay. I go back home. I read about it and I say, Okay, if that is the case. I don't think I want this for this child. I'm from a Christian background, so I just applied my beliefs to that. Okay, this cannot happen to this child. I don't have this in my family. Where in the hell did you get this?

During the interview, Lisa mentioned her Christian beliefs several times in her description of dealing with an autism diagnosis. She shared that she had mixed support from family due to some family members being in denial and not understanding the autism spectrum. She reported 'praying often and family giving her advice. "They encouraged me, 'You have to pray,' and all that. I mean, more of a Christian thing. That religious aspect, that's what it says, you have to pray, you have to fast and all that." Lisa also noted the support from the family member that encouraged the developmental screening. She said, "he just talked to me that I have to ensure I get him enrolled for [Preschool Program for Children with Disabilities] (PPCD) and let him start school early so that they can help him and all that." Lisa told the researcher that she didn't tell many people about her son's diagnosis. She shared:

I didn't really tell people because it wasn't something that I accepted as a mom. As the mother, it's not something easy for you when they tell you, like I have said, you find it difficult, you don't want to accept. You deny that. No, I don't want to accept that. From my own side, from my own family, the support from my own family is more a spiritual thing that I have to pray about it.

After they returned home from visiting family out of state, Lisa stated that the family participated in a second evaluation, and she was referred to ECI. Her child received in-home Early Childhood Intervention (ECI) services until close to his third birthday when he was referred to the LEA (Local Education Agency). Lisa did not report

any difficulties accessing ECI services and reported a smooth transition from ECI to the LEA, stating, “there was no problem or anything. It was easy.”

Lisa’s son participated in a district evaluation, and her child began receiving services through the school after his third birthday. She reported that the evaluation through the school district was the third evaluation. Lisa reported that she received support from evaluators during the evaluation and when reviewing information but still had difficulty with the autism label.

One side of me accepted all the things they said, one side of me said, no, I can’t take that. But the reality of this is for my child, so I didn’t even have a choice to the point that I just have to accept whatever thing they said. They gave me the information that I needed, the support, they did.

Lisa’s son is now 11, and she shared that she still has difficulty accepting his autism diagnosis at times. Lisa reported that previously, she would get emotional if a teacher called her with a problem. “Before any little thing like this, anytime if the teacher calls me, I’ll start crying. Every little thing just gets me. If they send me a note that your child didn’t do this, I will be crying.” She shared that as time has passed, she doesn’t have the emotional reaction and

I try to control myself like, ‘Okay, how can you help him? If you cry from now, it’s not going to help him.’ You just have to think outside the box, how you can help this child to get to the level he needs to get to in life.

Lisa reported that her son began receiving services “immediately” and received services in a self-contained Early Childhood Special Education (ESCE) program, previously known as the Preschool Program for Children with Disabilities (PPCD). He also received speech and occupational therapy through the schools. Lisa reported that after her son began receiving school services, she took him to a provider recommended by the daycare,

but she felt that they were after money instead of offering services that would improve her child's development. She did not access any other support services for her child outside special education services through the LEA.

When asked if there were any additional services she would have liked for her child, Lisa reported that she was overall satisfied with the school services but wanted her child in inclusion. She advocated for her child to be in an inclusive setting but was told that it was not appropriate for him. Lisa reported that her lack of knowledge about autism and services initially had her concerned about her child's education. She said,

The mental picture that I had then was, okay, when the child has one form of disability, I was thinking, "Is he going to be with the imbecile kids? Is he going to be with kids that are really, really, in their case is so severe?... But I was thinking he was going to be in the classroom with kids that are imbeciles, the ones that are half slow, that severe level of disability. That was my thoughts, but I found out that is not the picture.

Lisa also reported some frustration with the school because she thinks expectations were lowered for her son educationally due to his disability. Lisa said, "I feel it's not just my son, it's a general thing, any child that has any form of disability, they limit your learning." She believes that her son can learn more because when she works with him at home using visual supports, he can do the tasks. She said she knows he gets the same support at school, but she feels "they limit what they learn because they just don't want any behavioral thing, they don't want to trigger any behavioral issues." She shared that, while her son has had good relationships with all his teachers up till now, she thinks they are not positive enough with her son and in their expectations for him. She believes that some teachers think, "Okay, the child has this, has that. Okay, the child can't do nothing. I'm just going to let him do whatever thing he can do." She also reported concerns earlier

in his elementary years, with teachers often calling regarding classroom behaviors. While Lisa said she understood while teachers were keeping her informed of what was going on, she wished they would have also handled his behaviors during the day without calling her as often. She feels that:

Whatever happens in the classroom, you should be able to manage the child. But if it gets out of hand, okay, you can call the parent. But if it's something you can manage, why not go ahead, and manage it instead.

Lisa acknowledged that her child can be aggressive, but she feels that his teachers should know how to handle his behavior, or they shouldn't be in the classroom. She reported the emotional toll it took on her receiving so many calls during the day about her son's behavior that she avoided phone calls from the school at times. Lisa reported receiving calls from the school telling her she would need to come to pick him up due to his behavior. She felt that they should have the resources to handle behavior during the day. Lisa stated that the school has a behavior intervention plan (BIP), so she didn't know why they called her instead of implementing the plan. She reported concerns that teachers didn't always understand her child or the spectrum. She said she understood that all students in the classroom need to be learning but that she couldn't always change her schedule to come up to the school and pick him up. With that being said, Lisa did report that her son has benefitted from the school services. He has improved his social skills and loves math. He has improved in his speech, and she has seen more positives. In closing, Lisa shared that it can still be hard that her son has a disability even with his progress. She stated that:

As time goes on, I appreciate all the teachers for their hard work. And I don't wish for any parent to have a child on the spectrum. I don't wish anyone to have

that because it takes a lot from you. It takes a lot, a lot, a lot for the parent and also the teachers.

### **Catherine**

Catherine has a daughter with ASD. Catherine's concerns for her daughter's development began at birth. She shared that her daughter is a twin and was born prematurely. Her daughter was in the NICU, and Catherine reported that general developmental concerns were apparent early in her life. Catherine's daughter had seen many specialists for her developmental concerns, but the focus hasn't been on autism. Catherine's daughter had feeding issues as well as vision issues. Catherine told the researcher that initially, her concerns were not listened to by the physicians. She shared that her daughter "has been a headbanger her whole life since she could lift her head, and everyone would just kind of brush me off and say, 'Oh, she'll grow out of it'."

Catherine's intuition told her that the development wasn't normal, but initially, she felt her concerns weren't listened to. At her daughter's two-year well check with the pediatrician, Catherine filled out forms for the physician. Based on the results, the pediatrician recommended Catherine get her daughter evaluated. Almost simultaneously, the neurologist that they had been working with also mentioned concerns but said he was not going to diagnose her but that her daughter needed a full evaluation due to showing some signs of ASD. After medical professionals voiced concerns, Catherine said that "at that time, I kind of dug my heels in and was like, No, no, no, no."

Catherine's daughter began receiving ECI services at four months of age due to her early developmental delays. She was born with a laryngeal cleft and received feeding and speech therapy through ECI from four – 16 months of age. At 16 months of age, Catherine reported that ECI began to phase her daughter out of services due to providers believing her daughter would no longer show the delays needed to continue services.

Providers told Catherine that they felt her daughter still needed support, so Catherine was told to self-refer in a month to reassess her daughter's need for services. ECI services were discontinued when her daughter was 17 months old and then Catherine self-referred her daughter the following month, and services were again recommended. Around this time, the COVID-19 pandemic was beginning, and ECI services were offered virtually. Catherine chose to discontinue ECI services due to her daughter not benefitting from the virtual services. Catherine reported that her daughter is just now starting back with ECI services since in-person services are resuming.

During the interview, Catherine provided more information regarding her daughter's evaluation and diagnosis. Catherine shared that her daughter was officially diagnosed with ASD at two years and three months old. When going through the evaluation process, Catherine had support from her husband and nanny. She shared that her daughter was diagnosed by a neurologist in tandem with a developmental pediatrician. Catherine was provided with a lot of information from the evaluation, and while she does not disagree with the diagnosis, she does agree with the developmental evaluation for autism because it stated that her daughter was very low functioning. Catherine described her concern as a parent with the system as a whole:

You take a child that has either autism or social anxieties, and you put them in a strange doctor's office with two people they've never seen, and then you think like, of course, my daughter, she shut down, she wouldn't speak. Normally she is talkative, she is hyper-social... I feel like, as a whole, you can't get an accurate diagnosis if you put a child that already has difficulties in a strange environment. Catherine was in the evaluation session with her daughter. Evaluators observed her with her daughter, asked her to do several tasks, and tried some tasks with her daughter. The process took over three hours. Catherine remembers answering a lot of questions, and she



remembers a rating scale was included in the report, but she doesn't remember what the rating scales were but that they asked a lot of developmental and behavioral questions.

Following the evaluation, the results of the assessments were reviewed with the family after a break, but they were not given a report. Catherine had to request a copy of the report since she was told her daughter would need applied behavior analysis (ABA) therapy, and they needed a copy of the evaluation. Catherine asked for the evaluation to be faxed to them, but after several weeks, her husband had to take off work and drive to the Medical District (pseudonym) to get a copy of the report. When asked if she was given recommendations from evaluators, Catherine said, "that is one thing she did. She had a whole humongous printout of resources, recommendations, prescriptions, whatever." Services recommended were speech therapy, evaluations for occupational and physical therapy, and ABA therapy. The family chose not to participate in ABA therapy due to the time commitments, limited in-home options, and difficulties with paperwork and insurance for in-home options. Catherine reported that therapy would be 8-10 hours a day for her two-year-old, five days a week, and she felt it was just too much. Catherine reported long waits for ABA therapy as well, and locations without waitlists are not close to her home. Catherine reiterated the frustration of trying to get things done for her daughter and acknowledged that she can't give all her time to her daughter when she has other children who need to go places and have appointments. Catherine reported frustration with being told that early intervention is important and that every minute counts for interventions, but then she was told waitlists for services were over a year long. So not only did they have to wait a long time for the evaluation, but they also had to wait a long time to begin services.

Currently, Catherine's daughter has been approved for private speech and occupational therapy. Catherine has already contacted the school district and plans to have her evaluated for school services before her third birthday.

### **Jessica**

Jessica has a son with ASD who is presently nine years old. Jessica reported that the pediatrician first noted concerns at his 20 month-old check-up after administering the M-CHAT. The pediatrician told her it was probably a developmental speech delay but to go ahead and have him assessed for autism just in case. The autism evaluation was scheduled two months later when he was 22 or 23 months. Jessica reported that she still did not have concerns and thought the evaluation would be negative for ASD. A neurologist conducted the evaluation and diagnosed him with autism. After receiving the diagnosis, the physician referred them to ECI since her son was still under three years old, and she followed the doctor's recommendation.

When Jessica initially contacted ECI, they denied her son services because they told her that her son did not qualify due to not having significant enough delays. She had to follow up again with the physician and was given the correct verbiage to use when contacting ECI so that they would start services. Jessica was told to tell ECI that he was diagnosed with a medical disability and that it was illegal to refuse him services. Jessica reported that "I had a very good doctor helping me along the way." Despite all the effort, Jessica shared that they ultimately did not participate in ECI services due to receiving private therapy, but she still wanted to be under ECI to facilitate the transition to public school. Jessica reported that it was important that her son transition to school services, and she was told that transition could begin earlier if he was under ECI.

When going through to evaluation process, Jessica reported having support from her immediate family and private nanny. For extended family support, Jessica shared that:

One part of the family is very supportive, and then the other side of the family is in denial... They see he's so smart and so special. They are comparing. I think they're not seeing the difficulties that he has as barriers. And so instead, they're just saying that's how kids are, and they're not just seeing the quirks. And what they think of autism is not as a spectrum but as the severe intellectually disabled, very one extreme [end] of the spectrum.

Jessica's son was evaluated by her local LEA after transitioning from ECI. Jessica reported that ECI supported the transition and "I pretty much provided the paperwork, and the information, and the feedback to them and they took care of it, and it was very easy." The school district-based evaluation was conducted over several hours. Staff observed her son and interacted with him while she was working with another staff member answering questions. Jessica was in the room with him, but there were a lot of toys. Evaluators also observed her son in a classroom to see his interactions with same-age peers and determine his reaction to situations in the classroom environment, such as another child taking a toy. Jessica reported that she was able to talk about her son's strengths, weaknesses, and needs. After the evaluation, Jessica reported that they were not provided resources or recommendations for additional private services, but they were already accessing private therapies. The school did create a plan for services that included coordinated care with his current therapies.

After her son was evaluated, Jessica reported having to wait four months for her son to begin receiving therapies. After turning 3-years-old, Jessica's son accessed services through the school. He attended a half-day preschool program and a half-day of

ABA therapy. He also received speech and occupational therapy within his educational setting. Jessica reported that she was happy with the services recommended through the school. Her son continued to receive ABA therapy into his Kindergarten year until he graduated from the program. Jessica reported that her son still struggles with generalization, and they were told to access an LPC to assist with generalization. The transition from ABA, while exciting, was also stressful for the family.

Once we left the ABA and the ABA said, “Hey, he’s great. He’s doing so well. He no longer needs our services, but we see gaps.” We say, “But what services is next?” What kind of doctor, what kind of therapy do you go to next? The ABA clinics weren’t able to tell you where to go or have recommendations. So that was difficult, because the ABA clinic didn’t even know what came next and that an LPC could help with that.

She reported that she asked the ABA therapist, “so what do I do next to help with generalization? They said, ‘Well, do experiences and implement what we’ve taught you.’ And it’s like, yes, but what else?”

Jessica reported that one of the greatest difficulties she is currently having is with the school district. Teachers at school do not understand the variability of children’s behaviors on the autism spectrum and the subtleties that may occur for higher functioning students. That said, Jessica shared that her son is mainstreamed and is not presenting with concerns that limit his functioning in the general education classroom. She reported that all teachers are explicit with their directions and expectations at the elementary level for their students, so they do not see her son’s weaknesses. Jessica shared that her son is very literal, so when he was told they could not play on the swings because of COVID, he also thought that meant he could not swing on the swings at home in the backyard. She reported that:

We've worked so hard through early intervention to concretely teach him socialization skills so that he wouldn't be behind when he entered kindergarten or first grade. So, he is right now on par with his peers, and so much so that they want to dismiss him from special education because they don't see a difference between him and his peers.

Jessica reported that in her experience, the teachers often have an outdated view of ASD and think that intellectual limitations are a part of the disability, so they do not recognize that her son is still on the spectrum and needs ongoing supports.

Jessica's son currently receives speech therapy through the school for articulation, which is not a big concern for her. Her son no longer receives private speech therapy. When asked if her son has benefitted from the services he received, she said "absolutely." Her son was initially non-verbal. After starting speech therapy, she reported he could speak if prompted, but it was not authentic. He has been in both individual and group speech therapy, which has helped quite a bit to the point that she no longer has any concerns. Her son still participates in occupational therapy for sensory needs, but he is progressing, and services will begin to taper soon. Jessica reported that her son still has areas for growth, but she is happy with where he is after several years of intervention.

Jessica shared that she also has a daughter on the spectrum who is a year younger than her son. She shared that having gone through the experience once before made it so much easier the second time when accessing services for her daughter. Jessica reported experiencing more success the second time because she was familiar with the process of accessing evaluation and intervention services. Jessica reported that she feels that parents need support knowing where to go and what to do to access services as a parent. Jessica reported joining a social media group to find support and resources. She also reported

that she now helps other families who join the group navigate the system for diagnosing and accessing services for their children.

### **Robert**

Robert has a son with ASD. Robert reported having concerns with his child's development around 18 months to two years of age when his son was not meeting developmental milestones. Robert shared that "he wasn't really talking, wanting to be held, you know. He was difficult to calm down when he was upset. It was pretty off, you know." Robert stated that they shared their concerns with the pediatrician but were told to give it time. They did refer the family to ECI to see if he would qualify for services because of his speech and language delays. Robert's son qualified for ECI services and began receiving speech therapy. Around two years of age, Robert noticed his son was engaging in more atypical behaviors such as hopping and flapping his arms. Robert reported that a friend, who had a child on the spectrum, mentioned that his son might have autism, and he should pursue an evaluation. Robert shared that he thought his son might have behavioral issues but didn't think it was autism.

The family followed up with the pediatrician regarding an evaluation. The physician had the family complete a screener and then referred the family to a psychologist. The family contacted the psychologist who recommended they have the evaluation, but the waitlist was long and the family decided not to pursue the evaluation at that time. Robert continued to receive his ECI services for speech and occupational therapy until he transitioned to the LEA when he was close to three years of age. Closer to his son's third birthday, Robert's son was evaluated through the school district. Robert reported that he wanted to have his son evaluated through the district to see if he needed services. He reported that he was not sure if his son had autism, but Robert knew something was wrong and that his son would need help in school. When asked about the

evaluation experience, Robert told the researcher, “It was okay, a little nerve-racking, and the district did a good job evaluating him. After we got the report, it made sense to us as to why he had autism. You know, we were just hoping that he didn’t have it.” Robert was provided with recommendations for school services and given information about community programs and therapy services.

Robert shared that his son participated in the PPCD self-contained classroom and received speech therapy and occupational therapy through the school district. He reported that going through the school evaluation process was relatively simple, especially since they transitioned from ECI and were told the steps for the process. Robert did say that “we wanted more speech time, but he was making progress on his goals, so they didn’t change it, but I did think he would have made more progress if he had had more.” Robert considered obtaining additional private therapies for his child but the out-of-pocket costs for providers with shorter waitlists were too high. Robert investigated ABA therapy for his son, but it was too expensive. Robert expressed some regret for not accessing ABA therapy for his son because he feels his son would be farther along if he had received the therapy. Robert also reported wishing that he had started trying to get his son services even earlier. He reported having “no idea waitlists were as long as they were”, and if he had started earlier, they would have been able to get on the lists sooner. Robert mentioned that the demand for services for children with ASD is high, and there does not seem to be enough therapists. Robert expressed his frustration by saying, “having to wait six months is a long time when they are little. I mean. He was only three. Six months would be a long time in the span of his life”

## **Examiner Participants**

### **Alice**

Alice is an evaluator who works in public schools. Alice has eight years of experience evaluating and working with children with ASD. Alice shared that she evaluates children who are 2-12 years of age. In her experience, Alice sees children diagnosed with ASD around two to three years of age but did report that they have had several recent referrals for full autism evaluations at the high school level. Alice shared that the most commonly reported initial referral concern for parents of children with ASD, but the parent is unaware, is speech. Alice has seen more referrals come from Early Childhood Intervention (ECI) than usual in the last year.

When asked to describe the typical evaluation process, Alice shared that it depends on the student's age. With early childhood (EC) students, Alice stated that evaluations are conducted in the arena style with a speech therapist and occupational therapist present. Alice shared that the same team members are involved with school-age children, but the evaluation is done in pieces instead of in an arena setting. After assessing, they "come together as a team and kind of talk through all of our findings and pull it together in the end." Recommendations are provided to parents after the evaluation. Alice reported that they provide a lot of school-based recommendations to parents currently. She did note that "I have parents interested in private and outside services, and we're working at the district level to see how we can support parents that are seeking those types of interventions." Alice feels that parents get the most support from their child's ECSE teacher. Alice shared that the district recently hired a new transition person to help create more resources to support parents. Alice had a productive meeting with the new transition person the day prior to her interview with the researcher



and is optimistic that they will have even more resources for parents in the future. Alice reported that currently, she also has a lot of digital resources that she will provide parents.

Alice reports that the most commonly utilized community services students have accessed are speech therapy, occupational therapy, and ABA therapy. Within the educational setting, students commonly access the ECSE self-contained classroom, speech, and occupational therapy. Alice noted that they also are trying to get families “connected with our transition people so they can start thinking about the future and those types of services going.” Alice feels that school services offered currently are “sufficient” but sees the biggest gains from students who receive private therapies in conjunction with school services. She reported, “we see greater gains in that, because we see the carryover in the generalization of skills.” Regarding any needed services for families, Alice feels that:

The biggest thing is just equipping the parents. If they don’t have those outside services, equipping the parents to take what we utilize in school, and promoting that at home as well and practicing those things at home, just to have those reinforced skills.

Alice feels that parents may not be equipped to help their children access services because they are in denial regarding ASD and may truly believe it is a speech issue. She also reported that often children have better relationships with their parents, so behaviors may not be as apparent within the home setting, which may lead parents to think it is less of a concern. Alice thinks parents would benefit from “having more knowledge of, ‘It’s not just about in the home, but in the community as well’” when looking for services for their child.

When asked about her thoughts on services available based on the age of diagnosis, Alice feels that “the kids who have services earlier tend to have more

services.” Alice provided several examples of situations that can prevent parents from accessing services as early as possible for their children. She reported that, initially, parents might be told their child has a speech delay, but autism is not mentioned as a concern by early service providers. Alice feels that pediatricians can delay parents accessing services. “I hear a lot of parents go, ‘Well, we talked to the pediatrician, and they said that they were okay.’ It’s like, well, yes, they do a screener, but it’s not capturing the whole big picture.” Alice reported that the lack of endorsement from other service providers and pediatricians can make conversations with parents more difficult and delay students starting services. She reports that when parents have been given contradictory information, it will take additional time to break down strengths and weaknesses and developmental expectations.

In closing, Alice feels that the biggest way to support access to diagnostic and intervention services is:

Just general public knowledge. Not only as an evaluator, but as a parent of a young child myself, I don’t know what services are all out there. If I had a child with a disability and just not being aware and, I just don’t know what’s all out there. Knowing, even I in the evaluation world until I really sat down and worked more and more with the two and three-year-olds, I’m not even fully aware of all of the ECI services that are out there. I think it’s unless you’re in the world, you just don’t know.

## **Lyn**

Lyn is an evaluator who works in private practice. She also occasionally consults with school districts and has had previous experience working in public schools. Lyn has 15 years of experience working with children with ASD. Lyn works with families of students ranging from kindergarten age to adult. Lyn finds that children are typically

diagnosed with ASD in their elementary years. Lyn shared that she has seen a recent influx of immigrant families seeking evaluations because “there’s a slew of immigration attorneys around that are telling people that if their kid has XYZ diagnoses, then they can stay in America, so I’m seeing a lot of that”.

When asked about the typical evaluation process, Lyn reported that she usually conducts a full parent interview and will ask parents for examples of behaviors observed instead of yes/no questions. Lyn will also interview teachers and other caretakers when appropriate. She also includes “some type of broadband behavior measure... to look at any comorbid diagnoses or disorders.” Lyn shared that “more often, not incredibly often, but more often than in previous years, we’re also including measures similar to a mental status exam because we’re finding more and more co-morbidity with severe psychiatric disorders.” Lyn conducts her portion of the evaluation independently but collaborates with other service providers or medical professionals who work with the child. She feels that “it’s good to have different perspectives on things and how things may present in my office may look completely different out in the community.” Lyn shared that she tries to mimic the multidisciplinary approach to evaluations that are conducted in the school. Lyn reported that “the younger the kiddo is, the more time I spend asking adults and caretakers questions.”

Lyn provides recommendations as a part of her evaluations, stating, “that’s 90% of the point.” Recommendations are based on individual student needs. Lyn reports that parents “absolutely” access the services that are recommended in the evaluations. Within her setting, Lyn reported having:

a team of community-based therapists, psychiatrists, or whomever that I often refer to. Sometimes parents are just still, they’re still not really comfortable with

the diagnosis. I'll send them to another psychologist who has a different approach than I do and see what they have to say.

Lyn reports that the most commonly received services she sees children with ASD access are speech therapy and ABA therapy. She has also seen children working with behavior therapists and who attend social skills groups. Lyn shared that in her practice, she is trying to create a "one-stop-shop" experience for parents:

because then they don't have to go to 50,000 different places. They just have to go to one clinic with that integrated model. If you're already nervous, you've been to that clinic before, so you feel more comfortable, and you know.

Lyn does not feel that services that are currently offered for children with ASD are sufficient. Lyn reported that she has difficulty helping parents find resources for children transitioning from high school to young adults. She reports a need for:

Those life skills related to that for kiddos who are high functioning, they may be going to a trade school or to university, and navigating that transition is pretty challenging and there's not a lot out there that I have found that helps support that transition for the high school kiddos. First year off at university, how do you meet people? How do you not come across as weird or unapproachable or whatever? How do you show that you want to be friends with people? And what does that look like? Where do you go to find people?

Lyn reports there are many services available for children with more severe needs transitioning into adulthood and are not necessarily appropriate for young adults that are high functioning. Services may also be community-based and serve families of all economic levels. Lyn has observed hesitancy from parents from higher SES communities with "going to a place where people look different than they do, talk differently than they do or have different, from their perspective, different values."

When asked if the age of diagnosis impacts access to services, Lyn felt this was more related to whether students were in public or private school. “If they are private school in K through 12, then they may not know of those services. They may not know that they can access those services within the school district.” Lyn shared that she is working with a young woman who is in her first year at College State University, and she has always attended private school and was not diagnosed with ASD until three years prior. She reported that parents did not know their daughter needed supports because she was cognitively high functioning and could compensate. Lyn shared that her client wishes she had known sooner that she was on the spectrum.

In closing, Lyn shared that she thinks parents do not know what to ask for or about. After an evaluation, parents are given a lot of information, and they do not know what to ask. In her practice, Lyn makes a follow-up call to the family several days after an evaluation review, after parents have had time to process, to answer any additional questions. Lyn has found that:

In doing that, even if the parents were hesitant at first to accept the diagnosis or to seek support before, when that’s done, it’s another effort at building rapport and they feel supported and they know that we genuinely care and want to help and not just take their money.

### **Jane**

Jane is an evaluator who works in public schools. She works in an early childhood setting. The typical age of students that Jane works with are three to five-year-olds. Jane shared that she most commonly sees children being diagnosed with ASD between three and four years of age.

Evaluations are conducted in an arena-style with a licensed specialist in school psychology (LSSP), a speech-language pathologist (SLP), and an assessment team

teacher. Other providers such as an occupational therapist (OT) or physical therapist (PT) may be needed, but they are not part of the core team. Parents are often given the option of being in the room with their child during the evaluation, depending on their preference. Recommendations are provided after the evaluations. Jane shared that recommendations are “individualized for the kiddo.” She reported that “once we see them and we get parent information, we decide what the best course of action for our students.”

After the evaluation, Jane reported that most parents access services through the district. Jane feels that sometimes parents delay seeking services because “I think sometimes they’re afraid of what they are going to hear so they might postpone getting help.” She also mentioned that COVID concerns had kept some families away from the public schools in the last year. Jane reported that they do a lot of community outreach and hope families are referred by pediatricians or family members if children need support. Jane shared that “we’ve had single moms that have very little support. We’ve had big families that live together and have lots of support.”

Jane typically sees children with ASD access services such as ABA, speech therapy, and occupational therapy. Within the schools, students have access to Early Childhood Special Education (ECSE) and Pre-Kindergarten 4 (PK-4) programs. When asked about increasing access for families, Jane shared, “I wish that we had a pre-K three.” She also feels that families would benefit from full-day programs, not only for added intervention, which she supports but also for increased access for families who need full-day childcare. Jane shared that ESCE programs and half-day can make it difficult for some families who work to access services.

Jane feels that parents have reported problems with insurance, not knowing where to go, and long wait times from parents seeking services. In a perfect world, she would

want “more social workers in our districts to help, to access outside things. That would be awesome. “

### **Sandra**

Sandra is an evaluator who works in public schools. Sandra has 15 years of experience working with children with ASD. Sandra shared that she typically worked with students from ages 3 to 18. She shared that most commonly the youngest a child is diagnosed with autism is three years of age.

Evaluation processes vary by age, but Sandra reported that they “usually do it as a team and bring all of our results and information together to come up with a picture, an inclusive picture of the child.” Based on the evaluation, they will give parents as well as teachers recommendations. Sandra finds that parents access services recommended: “for the most part.” If parents do not access services, she feels that it can come from “Just the lack of knowledge. The lack of knowing where to go to get that support.” Sandra feels that parents may have the support of the pediatrician when seeking a diagnosis, but “I feel like they are isolated.” Sandra shared that many parents do not have a support system. Sandra shared sometimes parents reported that pediatricians don’t listen to concerns initially and want to give it time.

Sandra shared that she commonly sees children with ASD accessing ABA therapy and speech therapy. Sandra feels that offered services are “a good start, but I think it’s still very limited.” Sandra feels that parents would benefit from more in-home training that also focuses on self-care and language skills. “Parents always want their children to speak and to walk, those are the two main things, but I also think that there’s a lot that could be done with some in-home training with the parents and the child together.” Sandra reported that limited staffing impacts parents accessing services, especially when

they are state-funded. Sandra does not feel that the age of diagnosis plays a big factor in accessing services and feels that there are various services offered at different ages.

In closing, Sandra reported that she feels that the biggest barrier for parents is wait times. When parents “see that something’s not right and they’re searching for those answers, they want to find out as soon as possible.” Long wait times make for “such a long, tedious process, and they sometimes have to go to more than one person before they can get it done, and I think it’s just very frustrating.”

### **Jenny**

Jenny is an evaluator that works in public schools and has over 20 years of experience working with children with ASD. Jenny currently works with early childhood-aged students. Jenny sees children being typically diagnosed around three years of age, but she has seen children up to 10 years of age getting an initial ASD diagnosis. When seeking an evaluation, parents most often report communication concerns if they do not already report concerns with ASD. When asked if she feels that age of diagnosis impacted service access, Jenny reported:

We hope they get diagnosed as soon as possible. And with us, that would be hitting that three-year age range in order for them to start school in an educational setting, because we know that the sooner, we provide those interventions, and just like any disability. If your child has difficulty learning to read and dyslexia, the sooner we can really pinpoint those characteristics and that symptomology and get them diagnosed, then the better we know that they’re going to do. Because we all know that bad habits are difficult to break.

Jenny shared that parents obtain evaluations in several different ways. Parents can transition from early childhood intervention (ECI) or parents calling with developmental concerns. Jenny reported that parents can come to screening to determine areas in need of



evaluation, or if a student already has a diagnosis of autism from outside of the school, the students will skip screening and go straight to evaluation. Evaluations occur in an arena setting with the parents present. Jenny noted the importance of having parents involved in the evaluation:

But the good part is, the parents are able to observe that evaluation and are a critical part of that team. So, it's not unusual for a student with autism to really not do well on standardized assessments, even developmental assessments. They oftentimes cannot do a task on demand. And so, it's really great that we have a parent in the room so we can ask them a variety of questions and what they see in the home environment.

Jenny described their process as open with the parent, where they collaborate to plan for the student. Jenny feels that even for children with prior diagnoses going through the district for evaluation allows parents to talk about any concerns. Consistent evaluation team members are an LSSP, SLP, and special education teacher. Jenny reported that sometimes the occupational therapist is involved if there are sensory concerns. For students with physical limitations, physical therapy can also be accessed. During the evaluation, examiners will talk to parents about observed behavior. During the evaluation process, Jenny shared “that we try to establish a solid and an informational, and a good relationship with the family, from those very first encounters.”

Jenny feels that over the last six years that she has been in her current placement, she has seen an increase in the number of students with a prior ASD diagnosis. In her observations, “doctors in the community are getting better about seeing those symptomologies.” When a child has a prior diagnosis of ASD, Jenny feels that “it's much easier and the flow is smoother, really from both standpoints for the school district, and [evaluators], just because they have already been seen outside of the school setting by a

medical professional as well.” After the evaluation session concludes, Jenny’s team will write a report and outline any educational eligibilities and proposed goals and objectives, and recommendations for working with the student.

Commonly accessed school services that Jenny reported are preschool classrooms or self-contained classrooms. They may also get speech and occupational therapy. Parents will often report that their child receives private speech therapy or occupational therapy. When asked if parents access services, Jenny feels, “For the most part? Yes. We’ve only, I personally, through our team, have only had a handful of students through the years that have chosen not to.”

Jenny reported that a current potential obstacle for parents wanting to access services is the pandemic. Jenny referenced children with higher medical needs and that parents are concerned. Private therapy, especially ABA, can be very cost-prohibitive even for families with insurance. Jenny reported that the experiences of friends and family members could impact access positively or negatively depending on their experience. Jenny reported that another factor that can delay a parent accessing services is trying to correct behaviors before the student starts school. Jenny has worked with several families who reported that they wanted to “work on it themselves, and see if their kiddos make gains over the next year or so.” Transportation limitations and work schedules can also make parents unable to access services.

While Jenny acknowledges that physicians are doing better with picking up on ASD symptomology,

I just wish that more family care physicians, primary care physicians could see more of the symptoms, or I wish they could spend more time with families and their patients when they come through. But, I think we’re a product of insurance and healthcare systems, and some insurance programs cover autism, some don’t. I

think as insurance companies have been forced, “forced” to provide services to cover autism, then they’ve relinquished provisions for other services. For example, several insurance plans will no longer cover speech and language services if the child or patient doesn’t have a primary disability of autism. Positive factors for service access that Jenny has seen are when families have good relationships with physicians and providers where “they trust their doctor.” Parents who have a good experience with ECI also seem more open to services. When asked about the support parents have when going through the evaluation process, Jenny shared,

Families are complicated, so some families have support, some do not. Sometimes it’s interesting, we’ve had families, particularly mothers that come through and they’ll say, ‘Well, I have concerns with autism, but my family doesn’t believe me.’

Parents have shared that they are told to discipline their children more and blamed for behaviors. Jenny shared that about 50 percent of parents probably have support systems. She shared that “I think as a family when you have these concerns with your child, that can be very alarming, and very lonely and very scary. So that adds to all of those, that fear factor for not only your child, but just knowing you don’t have some family support.” She also mentioned seeing increases in grandparents who are raising their grandchildren.

When asked if she felt currently offered services were sufficient, Jenny feels that parents are so inundated with information that it can be overwhelming. Some providers are out there, but the quality of services can vary as well as the out-of-pocket costs. Jenny feels that there could be more therapists but shared when therapists are working with children with ASD, they are also:

working with behaviors, and just task compliance. And so, you have to have a strong knowledge and background, I think of behavior to provide those services. A lot of therapists just don't have that background, or it's so exhaustive. And that initial progress can be slower, that I just don't think a lot of therapists want to work with students that have that particular profile, or they feel they just don't have the skillset to work with them, and the progress can be slower.

Jenny reported that school services vary from district to district, but if you “truly follow the model of time that a student with autism needs, [parents] probably feel like the schools are not able to give them enough because the schools and resources are also limited.”

In closing, Jenny feels “if we know better, we do better. That terminology, and I wish that, I think we're making such strides when it comes to children with autism, but we haven't even hit the tip of the iceberg yet.” Jenny feels that increased collaboration between schools, medical professionals, daycare providers would help providers “understand the symptoms a little bit better, or the signs to look for, and then, they could have those conversations with parents early on.” Jenny knows that those are tough conversations, and no one wants to offend a parent, but “the earlier those discussions are had, the better.”

### **Barriers to Obtaining Services**

The following are the most commonly reported barriers to accessing services for children with ASD, as mentioned by the participants. In order to determine the salient barriers, qualitative data from the parent and evaluator interviews were analyzed using an inductive approach to answer the research questions. The researcher then analyzed the data by coding and categorizing to determine salient themes. The barriers that were most

prominent across evaluators and parents were limited knowledge of ASD, service accessibility, and difficulties navigating the system.

### **Limited Knowledge of ASD**

Parents interviewed consistently reported that they had limited knowledge of ASD before their children were assessed. Lisa shared:

When we were back home, I didn't notice anything and also, I didn't even know some of the symptoms of autism. I didn't even know anything about that, not until we got here. But back home, there were things he was doing, but I probably didn't even think maybe all these milestones he has achieved then it probably would be evident straight away.

Catherine also reported this limited knowledge and denied having early concerns with autism. Catherine shared, "I knew really almost nothing about autism." Concerns with autism arose when they hired a nanny with an educational background and experience with special education and working with children with ASD. The nanny began pointing out behaviors that were of concern. Catherine said, "I had general concerns, but I wasn't sure what preemie versus like is there an issue?" Similarly, Jessica reported that she did not initially have concerns, but the pediatrician first noted concerns after administering the M-CHAT at a well-child visit. Jessica "relied on the medical professionals for suggesting and referring." Robert reported not knowing much about autism before seeking out an evaluation. Robert told the examiner, "Of course, I'd heard about it. It just wasn't really. I didn't really know much about it."

Evaluators commonly reported that parents know their child's development is atypical but don't necessarily know that it is autism. Sandra reported that "parents know that something's different, but they don't necessarily know what to label it or what it's identified as." She finds that parents are most often seeking evaluations because they

“want answers to what’s going on so that then once there’s answers and they’re looking for support. They’re looking for support for their child and for them on how to best support their own child. “

Alice finds that “about 75 or 80% of our parents have some inclination” that their child may be on the spectrum when parents come to the school to seek an evaluation. She shared that if a child does not already have an outside diagnosis, there is “a good 20 to 25% that it’s not really on their radar and we’re kind of the first people to initiate.”

In Lyn’s experience when parents seek her out for an evaluation, she reported that they typically have autism as a concern. She also reported that sometimes “parents come in and say specific hypotheses [that] I’m not allowed to consider in their opinion, and then we talk about that and process that.” Lyn reports that “most of the time, I have parents just wanting to do right by their kids.” Lyn reports that the families she sees have already been prompted by the pediatrician that something is different. She shared, “[parents] know something’s different. They’re usually exhausted from that something different that takes place all day, every day at home and getting the phone calls from teachers.”

When Jane was asked about parent referral concerns, she shared, “I think that it runs the gamut. We have families that have that concern already, or their pediatrician has referred them. Sometimes they just have language concerns.” In her experience, parents typically report the most concerns with language and social skills.

Jenny reported that even parents who do not have a diagnosis usually report that the doctor had concerns or someone mentioned concerns to them. Jenny feels that parents are not always honest with initial concerns from other professionals because they want to see if the evaluators see the same concerns. Jenny thinks this occurs because parents “want to see what another group of individuals think. And so, they don’t always share

that information with us upfront, but through either screening or through evaluation, our LSSP can ask those probing questions, and then it eventually comes to light.”

Despite parents reporting having limited knowledge of ASD, all of the families interviewed had children diagnosed before or around three years of age. Evaluators reported they are seeing children diagnosed at young ages as well. The age of diagnosis ranged from two years up to elementary years, with the most common ages being reported between three and four years of age.

Across parents and evaluators, there is a continued need to educate parents on ASD and ASD symptomology so they can seek out diagnostic and intervention services as early as possible for their children.

### **Service Availability**

Parents consistently reported difficulties accessing appropriate services for their children, including both diagnostic and intervention services. Many concerns were reported when seeking private therapy services or private evaluations. Evaluators also reported that parents are having difficulties finding services and providers for their children in a timely manner. When discussing finding services, “frustration” was often used by both parents and examiners to describe this process. When addressing service availability, the salient themes were difficulties navigating the system, waitlists, and insurance difficulties.

### ***Navigating the System***

Three of the five parents interviewed reported difficulties working through the diagnostic process and intervention services and difficulties navigating the system to access those services. Catherine described her experience accessing evaluation and intervention services for her daughter as being very difficult and time-consuming. She shared that “once there was a concern, it was super difficult for me to navigate even

where to get her evaluated. First of all, the waitlists everywhere are like 11 months long”. Catherine reported that her daughter was on several waitlists, and her neurologist made a call to try and move her up the list due to his concerns. At one point, Catherine was thought, “wow, she’s going to be like three or four before she can even be evaluated.” She reported systemic limitations and difficulties getting records from and to other medical professionals. Catherine summarized her frustration:

I didn’t know where to go, there’s like a billion different documents and paperwork, and they almost make it impossible to get an evaluation because they need like all the medical records and City Hospital (pseudonym) couldn’t connect to Metro Hospital (pseudonym), they couldn’t seem to get the paperwork that Metro Hospital needed. And City Hospital was saying they sent it, and Metro Hospital said they never got it. We did that for months, and that’s where it was really, really difficult. Once the doctors got on board and were like, ‘She needs to be evaluated,’ they kind of just were like, ‘Okay, well have her evaluated. Bye.’ And I’m like, I don’t even know where to start.

Catherine reported receiving conflicting information on which services were offered and at what age determinations were made. “Frustration” was used several times during the interview to describe Catherine’s experience accessing services. She described how it felt as a parent being told “you need to do something for your child but then being told it’s a year wait for her to even be evaluated.” She shared that the most frustrating part was how much time she spent researching, as a mom, just trying to navigate the system “who has no background in medicine or mental health.” Jessica shared that the process to access services was very difficult and continues to be difficult. She referenced waitlists of up to 18 months for new patients. Jessica shared her experience below:



As a parent with a new diagnosis, you want to do everything you can now and get it fixed. It's like saying you have cancer and everything the doctor is telling you, and all the research and articles you read, because you pour yourself into this now, is saying early intervention is the key. And when you call for an appointment to an ABA clinic, for example, or speech clinic, or occupational clinic, they have to do their own evaluation because they have to see at what level the child is at. And so, in order to get an evaluation, you have to go through insurance. So, they have to wait for insurance to respond, and then you have to wait for an appointment for an evaluation. And then, they have to evaluate, and then you have to wait for the results of that evaluation. And then, after that evaluation, they'll tell you whether or not they have room in their clinic to fit you. So, it could be that after insurance approves an evaluation, you go and wait for an appointment for an evaluation. And they say, 'Yes, your child definitely is in need of OT, or speech, or ABA. We would recommend X number of hours per week or per month, but we don't have room in our clinic, so you'll have to go somewhere else.' and then you have to start the process all over again.

Jessica reported that as a parent, she was "just trying to figure out what's the best thing to do and get it started as soon as possible."

Lisa similarly described her experience getting an ASD diagnosis as a "long journey" where her child had multiple evaluations to access ECI and school-based services. When describing the third evaluation conducted through the school district, she shared,

That was the third. It was emotional, I didn't accept it. In my heart, I was just praying the Lord, "I don't want this. Any negative report, I don't want it for this child. I don't want this, take this negative report. They were saying same thing,

but I was so emotional, it wasn't something I really wanted to hear. It was really emotional for me. It was really emotional.

Evaluators also report hearing similar difficulties navigating the system that parents reported. Alice sees parents that parents:

don't know where to start. They don't know who to call. They just don't know where to go. Or they have so many places to call or so many different contacts, they just really need someone to kind of sit with them and say, 'Do this, call this number.'

Often, the parents "who are, have more financial abilities tend to access more support and seek that out" than parents with fewer financial resources.

Lyn reported that the two biggest factors she sees preventing parents from accessing services are money and not knowing what services are out there. Lyn shared that one thing she does in her practice is "serve as an information broker for parents, and we're contacting community organizations for free and reduced costs services. We're contacting other private practices for other disciplines." In her experience, more educated parents and higher SES parents are more likely to seek out services. She finds that parents are more comfortable seeking services from places they have heard of before. She also thinks service recommendations from other providers can make parents feel like looking for services is "less like a cold call." Jenny also reported that parents are overwhelmed with information and finding providers that meet an individual family's needs can be difficult.

### ***Waitlists***

Another commonly reported difficulty when accessing services was the waitlist for evaluation and therapy services. Waitlists and difficulties navigating the system overlap some in parent reports, but waitlists were specifically mentioned by almost all

participants as a hindrance to accessing services. Typically, waitlist times reported by participants for services ranged from several months to over a year. Catherine reported a waitlist of 11 months when looking for services for her child. She shared, “if someone tells you a year-long waiting list and you’re like that whole year is going to be wasted, so you’re calling everyone.” After getting off the waitlist, Catherine reported that there are limited options for times and days for therapy. She reported that ECI was easier to schedule, but other therapy places either have limited schedules and limited locations that offer services. Catherine reported feeling like she would have to “make it work” with the scheduling conflicts because she wants her daughter to have therapy. Catherine feels:

There needs to be more services and more accessibility. I am so blessed that I have the time and support, and I’m home with my kids and the money to commit to this. But there’s so many families I’m sure that don’t. And even for me, that has everything in my corner, it’s been so difficult to get her services. I can only imagine for people with more roadblocks in the way, how impossible it would be.

Jessica reported that when looking for services, there was up to an 18-month waitlist for some providers. Jessica reported having to wait four months after her son was evaluated to initiate services. Further, Jessica shared that finding services was “very difficult and continues to be very difficult.”

Robert also referenced a “huge waitlist” when attempting to get his son evaluated by a private psychologist and chose to wait to go through the district instead. Lisa reported that there were only a few months between appointments for her son, but she did not access private therapies outside of the school district after a negative experience with a provider where she “didn’t like what I saw.”

Evaluators corroborated parents’ reports of waitlists for services and the difficulties that can cause for families. Jane, Jenny, and Sandra explicitly mentioned wait

times as a concern that parents report. Jenny summarized that the waitlists for “speech, language therapy across multiple agencies can be 60, 70, 80, over 100 kids long.” Since July, she reported having at least 20 families call and say their child has been evaluated but needs services. Jenny feels that parents:

can usually get in for the evaluation, but then they’re on this waiting list. They’re seeing us four or five months later, and they’re still on that waiting list. So, that’s a two-prong question because it’s a lot of times, families can get their child evaluated, but yet they can’t get the service.

Sandra reported similar concerns with waitlist for families. Sandra shared, “there’s a huge waitlist, and a lot of parents will go a year before they...and they end up just saying never mind or not following through with it just because they’re so frustrated.”

Parents and examiners reported the need for increased service availability for children with ASD. Parents report frustration with not being able to easily access services for their children after they have been diagnosed. Examiners reported similar concerns for parents who are trying to access services for their children.

### ***Insurance***

Another reoccurring concern reported by both parents and evaluators is delays or limitations in services due to difficulties with insurance. Three parents, Robert, Catherine, and Jessica, reported difficulties with insurance when accessing services. Catherine reported difficulties finding places that take certain insurance policies and getting approval from insurance for supports and services. Catherine reported that she could not access in-home ABA therapy for her child because “insurance things weren’t working out.” Jessica reported:

In order to get an evaluation, you have to go through insurance. So they have to wait for insurance to respond, and then you have to wait for an appointment for an

evaluation. And then, they have to evaluate, and then you have to wait for the results of that evaluation. And then, after that evaluation, they'll tell you whether or not they have room in their clinic to fit you.

Robert also reported delays due to insurance. Robert shared that his son participated in private speech therapy once a week when he was younger. While his son made progress in therapy, accessing the therapy was very difficult. Robert shared that “also, our insurance wasn't great at the time. It was hard to find places that took it, and then it was hard to get insurance to pay for the therapy. Uh, outside of a few a year.” Robert reported that his family did not have money to pay for private services out of pocket. Robert reported that after his son was diagnosed with autism, he was able to receive Medicaid, “so that made it a little easier, but there was still a lot of hoops to jump through.” Robert mentioned several times during the interview that his insurance made it hard to obtain services. While it was easier when his son was eligible for Medicaid, he shared that “sometimes it was hard to find places that accepted Medicaid that didn't have a waitlist.”

Evaluators also expressed that parents have limitations due to insurance. Jane shared, “We hear about problems with insurance, we hear about long wait times at City Hospital (pseudonym), and I know that's just part of the nature of their ... evaluation process.” Similarly, in her experience, Jenny finds that “some insurance programs cover autism, some don't. I think as insurance companies have been forced to provide services to cover autism, then they've relinquished provisions for other services.” Jenny reported that some insurance companies “no longer cover speech and language services if the child or patient doesn't have a primary disability of autism.”

Parents and examiners had concerns with insurance covering services for children with ASD. Parents reported the difficulties of working with insurance to get services

covered. Examiners also have seen families have difficulties getting insurance coverage for needed services for children with ASD.

### ***Out of Pocket Costs***

Another reported difficulty that coincides with the insurance difficulties is high out-of-pocket costs that can come along with services. While it was affordable for Catherine’s family, she reported that places “require like a \$500 deposit. I could see how a lot of families wouldn’t just have that off the top to put a deposit down, to get speech for their kid.” Lisa shared her negative experience paying for additional services. She reported that she “just didn’t like their service in the sense that I felt they were after money.” Lyn and Jenny both referenced high out-of-pocket costs as a barrier to services for families. Jenny reported that parents accessing ABAS programs may be looking at “\$2,000 to \$4,000 a month for ABA therapy. She reported that often services cause “significant financial obligations for families.” Lyn reported that she sees money as one of the top two barriers for a parent seeking services in her practice. Several evaluators feel that families that are higher SES or have more money have more access to services. Alice shared, “The parents honestly, who are, have more financial abilities tend to access more support and seek that out.” This sentiment was echoed by Lyn, who sees that parents that are of high SES tend to seek out more supports.

Parents and evaluators reported consistent barriers to service access due to difficulties navigating the system, waitlist, insurance, and high out-of-pocket costs. These barriers are prevented parents from accessing needed services for their children as soon as they were recommended. Parents reported trying to get their children support that they require but barriers delayed access or prevented access all together.

### **Working with Families from Diverse Backgrounds**

Of the parents surveyed, one parent reported that they were not from the United States and referenced her cultural background as one of the reasons she wasn't as familiar with autism symptomology. Lisa shared that her family is from Nigeria. Before moving to the United States, she reported that she did not recognize developmental concerns in her child. She shared that "In Nigeria, we don't have such disability so much among the kids. You might have ADHD but autism and other forms of disabilities, they are not common over there."

Given the metropolitan area in which participants were solicited, all evaluators reported having worked with families from different cultural and ethnic backgrounds and indicated that families vary in their acceptance of ASD and ASD symptomology based on their cultural backgrounds. In her experience, Alice feels the perception and acceptance of ASD vary by culture. For some families, she sees that "they're more willing and open to the services than the actual diagnosis." Alice reported having the most experience working with European and Middle Eastern families. Alice thinks:

The word 'Autism' is very loaded. I think the more that it's out in the world and publicized and things like that, then parents have this perception of what autism looks like and aren't really aware of the full spectrum of the disorder.

Lyn also has experience working with families from different cultural and ethnic backgrounds. She has worked with "Asian-American families, such as of Taiwanese heritage, Japanese heritage, Muslim from Iran, Pakistan, Hispanic and African-American [families]." Lyn reports that in her experience, "the less acculturated a family is into the predominant culture here, the less receptive they typically are, from my experience, the less receptive they are to the autism diagnosis, services, support, things like that." She reported that parents might feel this way because of:

weariness with the culture, awareness, a hesitancy to trust that their way of doing things will be honored or not seen as less than, that their way of doing things would be valued and incorporated in the assessment and treatment process. She also shared that, depending on a family's immigration status, they might not feel comfortable making themselves known. They may feel like authorities may find out, impacting their ability to stay in the country.

Jane also reported experience working with families of many different cultures and ethnicities over the years. Jane feels that different cultures and ethnicities can respond differently to ASD, but it varies. Jane feels that sometimes disabilities are not as accepted in some cultures, and extended families might not accept them.

Sandra shared that value differences can make evaluations difficult. She feels that parents are interested in services and may see how the behaviors can be related to a disability, but they may not agree with how behaviors should be addressed based on their personal beliefs.

I think those with the parents that are hesitant based on a different culture because they put their cultural beliefs and what they've been brought up to believe, above maybe, what the medical or the diagnosticians are telling them about the diagnosis.

In her experience, Jenny also sees culture influences parents and parenting expectations and affects their openness to disabilities such as ASD. Jenny noted that differences in parenting across cultures could also impact a parent's openness to disabilities such as ASD. Jenny provided an example of an experience working with a family and how families' cultural norms influence how they interact with their children. For example, during an evaluation, when asking how a student makes requests for wants and needs in the home setting:



some parents anticipate that need, and they not only anticipate it, but they also will hand feed them. And so, they do a lot of things for their child, so that a lot of times when we see them, and we talk about these different things that we see that if we have concerns of autism, they will say, ‘Oh, well, it’s because I allow him to do that,’ or, ‘He hasn’t had experience with that.’

All evaluators also reported a common practice of using interpreters for evaluation when appropriate. Evaluators may utilize the interpreters differently, but they were all used to facilitate parent participation and understanding between evaluators and families. Jane reported that interpreters are used to translate prompts and interact with family members. Jane feels that utilizing an interpreter when working with a family “makes them more comfortable, and then they probably do not miss anything that they may have missed because of a language barrier.”

When using interpreters and if they impact parent participation, Lyn shared:

I’m sure there’s some baseline improvement in participation, obviously, if they’re able to understand what’s being said to them, but I think another important factor, even more than commonality in language is rapport building on the part of the interpreter.

Lyn also reported that she works with a bilingual psychologist who will also act as an interpreter. Lyn reports that when acting as an interpreter, the psychologist “spends the first few minutes before we even do anything in the meeting, she just kind of chit chats and small talks to find similar interests and to work on building that rapport.”

Sandra reported that interpreters usually work with the family during the evaluations to complete parent questionnaires since they are response intensive. The interpreters also readminister prompts in the student’s home language. When using interpreters, Sandra feels that it makes parents feel “more relaxed. I think that it helps

them feel like they're being heard and if they have questions that they're being understood". Sandra reported that parents can ask for clarification if they do not understand something and the interpreter helps ensure that parents have meaningful participation.

During her evaluations, Jenny indicated that they always try to evaluate a student in their primary language. Interpreters are utilized to administer prompts in the native language, facilitate discussions with parents, and ensure that parents accurately report their child's skills in their native language. Jenny cautioned using a parent to interpret for their child due to evaluators needing to ensure that students are being given the specific prompts needed to elicit a wanted response. Jenny reported that since interpreters are neutral parties, they can accurately facilitate discussion between parents and examiners.

When working with families from different backgrounds, evaluators consistently reported the need to increase parent participation that is meaningful and noted that cultural differences and value differences can impact the evaluation process. The use of interpreters for evaluation seems consistent across evaluators with different utilization of interpreters but with the focus being increasing parent access and participation.

### **Summary**

Overall, parents and evaluators report the need for early intervention and services for their children with ASD. In their experiences, parents reported difficulties finding and accessing services. Parents did not report a need for new or novel interventions for children with ASD, rather they reported needing more availability of services that are already offered for children with ASD. Parents want services that are easily accessed, do not have a long wait time and services that are covered by insurance or do not have high out-of-pocket costs. Examiner experiences echoed parents' need for increased access to commonly recommended services for ASD such as speech therapy, occupational therapy,

or ABA therapy. Several parents and examiners also reported the need for services that span age ranges and levels of functioning.

## CHAPTER V: CONCLUSION

This qualitative study examined parents' and evaluators' experiences accessing services for children with ASD to gain insight into additionally needed services for children with ASD. This study sought to understand both parent and examiner perspectives of the process for diagnosing and accessing services for children with ASD. This chapter summarizes the finding of the study and the conclusions drawn from the data. This chapter also presents implications associated with the needed support for families of children with ASD as reported by parents and evaluators and recommendations for future research.

### **Summary of the Study**

The purpose of this study was to examine parent and special education evaluators' experiences accessing services for children with ASD and gain insight into additionally needed services for children with ASD. Specifically, this study examined parents' perspectives of children with ASD to capture their evaluation experience, process to gain services and examined barriers for families trying to access supports for their children. The study also examined evaluator experiences working with children and families to access services for children with ASD. Evaluators described their typical evaluation processes and gave their perspectives on programming and services needed to support families based on their experiences.

### **Findings and Discussion**

This qualitative study allowed parents and evaluators to share their experiences and build an understanding of parent and evaluator perspectives of current service availability. Data was collected through parent and evaluator interviews. From their experiences, several conclusions were drawn which align with existing literature and

introduce depth to some considerations to inform practices and supports for families. The findings are centered on the need to provide more extensive and individualized support for families, increasing and enhancing service availability for children diagnosed with ASD, and an intentional focus on meeting the unique needs of diverse families.

### **Parents need more support**

Parents from all backgrounds report needing disability-specific information, services availability, child-specific strategies, and information on general child development (Jung, 2010; Shannon, 2004). This study's findings support existing research that established parents need more information about ASD and interventions services. Parents reported having limited knowledge of symptomatology and, in turn, do not know where to go to access services. Evaluators reported that parents often know something is wrong but may not have ASD-specific concerns and, in turn, do not know where to start for evaluation or intervention.

Jimenez et al. (2012) found that communication problems between parents and physicians and limited understanding of the referral process can reduce the chances a student receives a diagnosis and accesses services. In this current study, several parents reported that they were not initially listened to by their physicians. Yet, other parents reported that the physician was the one who initially reported the developmental concerns. Even with this varied level of support, the typical age of diagnosis was around three years, which is consistent with the average age reported by evaluators and reported in research (CDC,2020b, Dawson, 2008; Jones & Klin, 2013). Consistent with findings in Self et al. (2015), when physicians are knowledgeable of ASD, administer ASD-specific screening and identify signs early, they can help children and families access needed services.

This study confirms prior research findings that parents have to be highly motivated when seeking services for their children (Pretis, 2011; Shannon, 2004). Parents and evaluators both reported the importance of parents taking an active role in obtaining services. Parents had to actively research and seek out services for their children. Evaluators also reported that families need support finding therapies and often do not know where to go or what to ask for when looking for support for their child. This is a critical element, and given that parents' lack of knowledge was a key theme revealed by participants, greater outreach is needed to increase parent knowledge and simplify and streamline the process of accessing services for families. Families reported needing more individualized services, more choices in services, and professionals working with their children (Carr & Lord, 2016; Lee et al., 2014; Pretis, 2011).

Given that parents in this study also referenced the difficulties of placing one child's needs over the others' needs in the family, individualized family support is necessary to navigate the dynamics of having a child with ASD on overall family functioning. This challenge was also reported by Shannon (2004), who highlighted families have to consider many factors when prioritizing the needs of different family members in light of the needs of their child with ASD. Fathers of children with ASD also reported a need for individualized family support and gender-specific support that, if not provided, leaves families less able to cope with challenges and can adversely impact all familial relationships and functioning (Potter, 2017).

### **Parents need increased service availability**

The review of the literature shows that parents need individualized services that allow for choice in times, locations, and providers (Lee et al., 2014; Pretis, 2011). This study confirms this need and captures the frustration many parents feel when told their child needs intervention as soon as possible, but the services are not immediately

available. Multiple parents and evaluators specifically mentioned the word frustration when describing service access. Frustration was reported when trying to obtain a diagnostic evaluation, initiating recommended services based on the evaluations, and accessing services requiring different service providers. For example, one parent reported that she was told her son no longer needed ABA therapy, but they could not tell her where to go next to access services. Waitlists, difficulties navigating the system, insurance, and out-of-pocket costs associated with diagnostic and intervention services compound that frustration.

Several parent participants reported not being able to access specific services due to their high out-of-pocket costs. Most parents reported insurance difficulties and limitations in approved services and providers. Consistent with the finding from research, the cost of services can frequently be a barrier for families seeking to access services for their child with ASD (Gray, 2002; Shannon, 2004; Sharpe & Baker, 2007). ABA programs were reported to be extremely costly by both parents and evaluators. Several parents reported that without insurance covering the services, the family could not afford them. Examiner statements also supported difficulties with insurance companies constantly changing what and how they cover services. Services not covered by insurance companies are a greater financial burden for families. Wang et al. (2014) examined Medicaid costs versus private insurance costs and services covered for ASD across 24 states. Across costs and services per child with ASD, Medicaid covered more than private insurance across total healthcare costs, ASD-specific costs, and medication costs. Medicaid also covered more speech therapy visits (13.0 visits vs. 3.6 visits), covered more occupational/physical therapy visits (6.4 vs. 0.9 visits), and more behavior modification/social skills visits (3.8 vs. 1.1 visits) than private insurance.

Mandell et al. (2016) examined the impact of state mandates requiring commercial health plans to cover services for ASD on the number of insured children diagnosed with ASD. Insurers have expressed worry that mandates will increase the number of children diagnosed with ASD and increase costs associated with their care. The study showed that mandates resulted in increased numbers of children diagnosed with ASD, which increased each year after implementation for at least the first three years following implementation. However, the prevalence of treated ASD was much lower than community prevalence estimates. This finding may lessen concerns that the mandates will substantially increase insurance costs, but it does suggest that many commercially insured children with ASD continue to be undiagnosed or are being treated only through systems that are publicly funded (Mandell et al., 2016). Mandates for coverage of ASD by commercial insurance companies would have greatly helped several participants access services for their children. Hopefully, with continued mandates for coverage, the frustration reported in dealing with insurance companies can be alleviated.

Literature reveals parents of children with ASD are limited in their ability to have employment while also accessing services for their children (Gray, 2002). One parent reported finding services for her child and taking her to services for an extensive amount of time. Parents also reported that the limited times and locations for services make it difficult to obtain needed services. Consistent with barriers reported by families, paying for services, insufficient free public resources, and high out-of-pocket costs for private services are barriers to gaining needed intervention for children with ASD (Sharpe & Baker, 2007).

Evaluators and parents confirmed the need for a more streamlined approach to accessing services. One examiner is implementing a process in her practice to help connect parents to services after their child is evaluated. Parents also need support



determining and accessing services throughout the life of their child. Even after their child is evaluated, parents do not know where to go next to find services. All parents reported that they received recommendations based on the evaluations, but there was no support to facilitate putting those services in place. Similar to the findings of Carr and Lord (2016), that increased participation in intervention programs was reported when families were supported through monetary funding and understanding of the families' needs, participants echoed similar sentiments in their experiences.

### **Families from diverse backgrounds have different values and require different supports**

In this current study, one of the parent participants reported they were not from the United States and referenced her cultural background as one of the reasons she was not as familiar with autism symptomology. Consistent with the literature, mental health stigma, the parenting approach, perceptions of developmental milestones, and help-seeking are influenced by culture (Zuckerman et al., 2017). As captured in the literature review, families of varying cultures reported experiencing denial of overt symptomatology and fear associated with a diagnosis of ASD that results in delaying services (Dababnah et al., 2014; Kang-Yi et al., 2018; Lobar, 2018; Lopez et al., 2018; Zheng et al., 2016).

Evaluators all reported varying levels of experience working with families from different cultural and ethnic backgrounds. All evaluators referenced the need to understand the different cultural values of families to best support them. This supports the literature that culturally and linguistically diverse families often feel that their opinions and culture are not valued, and parents are often judged and evaluated outside of their cultural norms (Cobb, 2014; Jung, 2011). School practices can be perceived as insensitive to families' values and may act with cultural assumptions instead of the

individual circumstances (Jung, 2011). Examiner experiences support this research that a family's willingness to participate in and seek services for their child is often influenced by their experiences and acculturation. Evaluators also reported that those families from different backgrounds might have different traditions and child-rearing practices that influence their perceptions of delays in their child. This is consistent with the findings of Cobb (2014) that found that parents of CLD diverse families are often judged and evaluated outside of the context of their cultural norms (Cobb, 2014). Consistent with the family systems perspective, the culture of families is a significant variable that evaluators should consider and value (Weeland et al., 2021). Family systems theory is a valuable framework to explore how and why families do or do not benefit from current programs. The added benefit of a family systems framework is that it can be applied to all family types and constellations. It offers an inclusive framework to assess family functioning and needs (Weeland et al., 202). Evaluators use interpreters when appropriate when working with CLD families. The use of interpreters to facilitate meaningful parent involvement is needed since the literature reported that CLD families often have difficulty successfully navigating the verbal and written exchanges needed to participate in the special education process. (Cobb, 2014).

### **Recommendations for Application**

The focus of this study was not only to gather the experiences of families and evaluators accessing services but also to look at what services are needed for children with ASD. As discussed in the previous section, the most prominent barriers to service are families' limited knowledge of autism and difficulties families experience navigating the referral and service systems, including insurance difficulties and wait times for services. All of the evaluators report providing parents with recommendations after the evaluations. All parents also reported they were given recommendations after the

evaluation or service providers, but they still reported difficulties accessing services. These barriers feed into the overarching need reported by both parents and evaluators that there needs to be an increase in providers and services offered and better support from service providers to get the family to the next step in the intervention process. Though this study is limited in size and location, the results do offer recommendations for improving access for families of children with ASD. These recommendations are described below.

### **Increased Practitioners and Service Providers**

The significant waitlists reported among respondents are consistent with a greater demand for services than providers. The employment of speech-language pathologists (SLPs) is projected to grow 29 percent from 2020 to 2030 (Bureau of Labor Statistics, 2021a). Occupational therapists' employment is projected to grow 17 percent from 2020 to 2030 (Bureau of Labor Statistics, 2021b). Projected growth across both professions is higher than the average growth across professions. Parents did not report a need for any new or novel intervention for children with ASD but reported the need for greater service availability and less wait time for those services. Parents reported limited locations, times, and providers for services that made it difficult to access services. In order for parents to seek out early diagnostic and intervention services for their children, an increase in providers, service locations, and times that services are offered is needed. Parents need therapy services that are local, cost-effective and available. Parents report significant waitlists are causing delays in critical therapies for children. Increasing the number of providers and the number of services offered to families can increase student access and improve student outcomes.

## **Service Coordination**

Parents and evaluators need better service coordination throughout the life of a child with ASD. Parents reported not knowing the next step in the process throughout many stages of their child's development. Parents need support knowing where to go for evaluation, knowing the next level of intervention, support finding specific supports such as an LPC after the child graduates from their ABA program or post-secondary services for adults with ASD. Once parents receive a diagnosis of ASD, they would benefit from support from diagnostic and service providers to access the recommended services. Parents need more than a handout or prescription for needed therapies. Parents need information on how and where to access services. The responsibility of making sure parents have the information needed to access services for their children falls on service providers and evaluators. As reported by evaluators, it is even difficult for someone in the field to know what services are available. Evaluators will need to take more responsibility for shepherding families and guiding them through the process of accessing services. This could be achieved by having hospitals and schools employ a parent/community consultant to help parents navigate the system and ease service accessibility. The consultant would be familiar with the various local intervention practitioners, familiar with insurance providers and coverage, and familiar with which services would most benefit each child. The consultant would also be familiar with community organizations, grants, and scholarships to help families access high-cost services.

## **Increased Opportunities for Early Childhood Education**

Increased opportunities for early childhood education for all students are also recommended. This could be provided through universal pre-k for all students. Universal pre-k would allow school providers to pick up early signs of ASD or other potential disability conditions, ensuring that interventions can be initiated quickly through the

school system. Universal pre-k also allows for varying levels of intervention to be provided to children with ASD instead of being placed directly into a special education setting. Early childhood services occurring in home, daycare, and educational settings are known to impact development positively. Children who participate in high-quality early childhood programs demonstrate school gains that can persist over the child's life (Barnett, 2011; Zachrisson & Dearing, 2015). Children who participate in early childhood programs are more likely to graduate not only high school but also obtain a college degree (Campbell et al., 2012). Muschkin et al. (2015) evaluated two early childhood initiatives in North Carolina to determine their effect on student placement in special education by the end of third grade. Results indicated that children who participated in the two high-quality programs were less likely to be in special education or still receive special education services by the end of third grade. This supports the next for high-quality universal pre-kindergarten to improve the outcomes for all students.

### **Increased Knowledge and Understanding of Different Cultures**

Evaluators working with children with ASD would benefit from their knowledge of different cultures and languages common in the district or area where they work. When an examiner is working with a CLD family, they should take time to learn about that culture and make themselves aware of cultural differences so that families can feel respected and that their culture is valued. Evaluators should recognize families as the experts on their children and support them in their role as their children's teachers. Evaluators should use a combination of professional knowledge and information from families to create developmentally appropriate practice, must also be linguistically and culturally appropriate and enrich the enduring relationships between children, teachers, and families. (Allvin, 2018). Continued use of interpreters is recommended to increase parent participation. Using interpreters with education and disability-specific knowledge

can also help parents understand and meaningfully participate in the evaluation and intervention process. Most licensure for evaluators who work with children with ASD requires annual continuing education hours on cultural diversity. This is recommended to continue so that evaluators can ensure that they are sensitive to the needs of different families and can provide appropriate and meaningful support.

### **Recommendations for Future Research**

Continued research is needed to explore further the differences in family and evaluator experiences accessing services for children with ASD. Despite knowing barriers and facilitators for participation, all eligible families are still not accessing services for children with ASD as early as possible. Programs need to be redesigned to welcome families and be easily accessible. The following are recommendations for future research.

Further research needs to be conducted to look more in-depth at culture and ethnicity and how that impacts the experiences of CLD families. This study had the experiences of one immigrant family from Africa. A greater representation of families from multiple backgrounds will allow a more in-depth look at culture related to knowledge and acceptance of ASD symptomology, thus allowing evaluators to be more responsive to the needs of the families they work with and better able to support them while respectfully valuing their cultural and ethnic differences.

This study was conducted with families and evaluators operating in a single state in which most participants were from a large metropolitan area. Additional research is needed across multiple states to determine if barriers reported in this study generalize to other geographic locations and contexts. The barriers that families reported in this study were seen across research. Still, additional research that looks at how experiences differ by location can help policymakers identify effective practices while also differentiating

what a universal issue experienced by families and evaluators is instead of an isolated issue associated with a particular location or demographic area. Comparisons of supports and services would also be beneficial for determining how much support for students results in the greatest gains and reduction in symptomatology.

### **Limitations**

The limitations of this study include that data is based on parent and evaluator recalled experiences. Recalled experiences are impacted by the perceptions of the individuals and are not objective. An individual's perception of an experience does not necessarily represent the reality of what occurred. The study was completed in Texas and may not be representative of all populations. Another possible limitation is that this research may not be generalizable to disability conditions other than autism. The honesty of participants and individual perceptions of events may not represent every parent's or examiner's experiences.

### **Conclusion**

In order for children with ASD to obtain diagnostic and intervention services as early as possible ASD, barriers that prevent parents from gaining those needed services must be reduced. The perspectives of parents and evaluators are important in determining how to better support families and allow for policies to be made to ensure no child is missing out on needed services.

The most commonly reported barriers are limited knowledge of ASD, limited-service availability, and difficulties navigating the system, including waitlists, insurance, and high out-of-pocket costs. Parents report needing more services and providers, shorter wait times for accessing needed services, and support in accessing and obtaining diagnostic and interventions for their children with ASD. Continued development and

expansion of programs offered for children with ASD are greatly needed to meet the need reported by parents and evaluators.



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APPENDIX A:  
PARENT SURVEY COVER LETTER

December 2020

Dear Parent/Guardian:

Greetings! You are being solicited to complete an online survey that will gather demographic information as well as allow you to provide contact information for further interview. The data obtained from this study will allow for the development of policies and interventions to find and fill gaps in service as well as address barriers to service access for students with autism spectrum disorders (ASD).

Please try to answer all the questions. Filling out the following survey is entirely voluntary but answering each response will make the survey most useful. This survey can take approximately 2 minutes to complete and all of your responses will be kept completely confidential. No obvious undue risks will be endured, and you may stop your participation at any time. In addition, you will also not benefit directly from your participation in the study.

Your cooperation is greatly appreciated and your willingness to participate in this study is implied if you proceed with completing the survey. Your completion of this survey is not only greatly appreciated, but invaluable. If you have any further questions, please feel free to contact Dr. Elizabeth Beavers ([beaversea@uhcl.edu](mailto:beaversea@uhcl.edu)) or myself ([siffords6139@uhcl.edu](mailto:siffords6139@uhcl.edu)). Thank you!

Sincerely,

Sarah Sifford, Ed. S, LSSP



APPENDIX B:  
EVALUATOR SURVEY COVER LETTER

December 2020

Dear Evaluator:

Greetings! You are being solicited to complete an online survey that will gather demographic information as well as allow you to provide contact information for further interview. The data obtained from this study will allow for the development of policies and interventions to find and fill gaps in service as well as address barriers to service access for students with autism spectrum disorders (ASD).

Please try to answer all the questions. Filling out the following survey is entirely voluntary but answering each response will make the survey most useful. This survey can take approximately 2 minutes to complete and all of your responses will be kept completely confidential. No obvious undue risks will be endured, and you may stop your participation at any time. In addition, you will also not benefit directly from your participation in the study.

Your cooperation is greatly appreciated and your willingness to participate in this study is implied if you proceed with completing the survey. Your completion of this survey is not only greatly appreciated, but invaluable. If you have any further questions, please feel free to contact Dr. Elizabeth Beavers ([beaversea@uhcl.edu](mailto:beaversea@uhcl.edu)) or myself ([siffords6139@uhcl.edu](mailto:siffords6139@uhcl.edu)). Thank you!

Sincerely,

Sarah Sifford, Ed. S, LSSP

APPENDIX C:  
PARENT INTERVIEW QUESTIONS

Parent Interview Questions

1. When did you first become concerned about your child's development?
2. What were your concerns?
3. What did you know about ASD at the time?
4. Was it a concern of yours that your child might have ASD? Why or why not?
5. Did you share your concerns with your physician? If so, do you feel like your concerns were heard to by the physician?
6. Did anyone encourage you to have your child evaluated for ASD (medical professional/service providers)? If so, who?
7. Did you have family support while going through the evaluation process?  
From which family members? How did they offer support?
8. Did you have support from other sources during the evaluation process?  
Friends? Other service providers?
9. At what age was your child diagnosed with ASD?
10. Did you have your child evaluated privately or through the public school?
11. Why did you decide to have your child evaluated at that location?
12. How was your evaluation experience?

13. Were you given resources and recommendations after the evaluation? If so, what were they?
14. Did you seek services for your child based on the results of the evaluation?
15. What services did you access?
16. How was your experience finding services for your child?
17. How long after your child received the ASD diagnosis were you able to begin services?
18. Did you encounter any difficulties when attempting to get services for you child?  
What were they? How, if at all, did you overcome the difficulties?
19. Were they any services that you wanted for your child that were not available? If so, what were those services?
20. Why were you not able to access them?
21. Do you feel your child has benefited from the services they have received?  
Why?
22. Any additional information that you would like to share about your experiences?

APPENDIX D:  
EVALUATOR INTERVIEW QUESTIONS

Evaluator Interview Questions

1. Can you talk to me about your experience working with students with ASD?
2. Do you work in a private or public-school setting?
3. What ages of children do you work with?
4. Do you currently evaluate children for the disability condition of ASD?
5. Tell me about the evaluation process.
6. Do you work independently or in a team for your evaluations?
7. Do you provide parents with recommendations for services after the evaluation?
8. How do you choose which recommendations you give parents?
9. In your experience, what age are children diagnosed with ASD?
10. When parents seek an evaluation do you find that they already have a concern with ASD?
11. In your experience, why do parents tell you they are seeking an evaluation?
12. Do you find that after the evaluation parents access services for their child?
13. In your experience, what are factors that might prevent parents from seeking support for their child?
14. In your experience, what are factors that encourage parents to seek support for their child?
15. What intervention services are commonly offered in the area in which you practice related to ASD?

16. Do you think the services offered are sufficient?
17. Are there services that you feel children would benefit from that are not available?
18. Why are they not available?
19. In your experience, does age of diagnosis impact services access? How so?
20. What are your evaluation experiences working with families from different cultures and ethnicities? What cultures and ethnicities have you worked with?
21. In your experience, do different cultures and ethnicities respond differently to the diagnosis of ASD? If so, how?
22. When conducting an evaluation for a student who are ESL or LEP, do you have an interpreter as a part of the evaluation? If so, how are they utilized?
23. In your experience, do parents report having support from other external supports (family/friends) to help them navigate the process of evaluation and service access?