Examining Early Identification of Autism Spectrum Disorders:

Improving Pathways Toward Referral and Diagnosis Through Records Review

by

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A dissertation submitted in partial fulfillment of

the requirements for the degree of

Doctor of Philosophy

(Educational Psychology)

at the

UNIVERSITY OF WISCONSIN-MADISON

2022

Date of final oral examination: 9/3/2021

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Acknowledgements

First, I would like to express my sincere appreciation to my advisor, Dr. Jennifer Asmus, who has provided continuous encouragement and guidance throughout my graduate school experience. I would like to thank her for providing wonderfully detailed feedback on drafts of my dissertation project, as well as extend my gratitude to her for fostering my professional growth and refining my skills as a scholar, teacher, researcher, and clinician.

Next, I would like to thank Dr. Gail Chodron and Dr. Lindsay McCary for the countless hours that they have invested in my personal and professional development. They both played an absolutely critical role in the conception and conduction of this research study, and I am incredibly grateful for their mentorship throughout the dissertation process. I would also like to recognize Dr. Daniel Bolt for his willingness to assist me in finalizing my study design, conducting my statistical analyses, and comprehending my data outcomes. I am incredibly grateful for his patience and unwavering support. Additionally, I want to express my deepest thanks to Dr. Steve Kilgus and Dr. Gigi An. I greatly appreciate all of their positivity, time, and feedback on my professional work. Further, I want to acknowledge Shuzi Meng for her willingness to assist with reliability coding of my data, as well as recognize all the patients and families who participated in diagnostic evaluation services with the Autism and Developmental Disabilities Clinic. Without them, this research would not have been possible.

Finally, I am eternally grateful for the love and support that I have received from family and friends throughout this process. I would like to express my deepest appreciation to my parents, Tracy and Jim Dorlack, and significant other, Doug Keating. This journey has not been an easy one, and each of you has made it feel manageable with your unconditional love,

acceptance, and nurturance of me and my dreams. I also want to thank the amazing women in my cohort – Abbey, Katie, Kelly, Maddie, Soobin, and Sophia. It has been such a privilege being able to learn and grow alongside each of you over the past five years, and I could not have asked for a more supportive group with which to face all of the triumphs and challenges of graduate school.

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Abstract

Early identification, referral, diagnosis, and intervention are critical to the promotion of lifelong positive developmental trajectories for individuals with autism spectrum disorders (ASD). Although psychometrically sound screening and diagnostic assessment measures exist and a reliable diagnosis of ASD can be made before children are two years of age, the average age of official diagnosis is well over four years. While research has shed some initial light on factors associated with delayed identification, referral, and diagnosis of ASD, all issues have been examined through population-level analyses based on retrospective caregiver self-report. Further, although suggested as an important research direction to confirm clinical information, no studies to date have analyzed factors associated with the pathway toward referral for ASD and subsequent diagnosis of ASD through examination of data reported in electronic health records. Thus, to address these limitations and develop a greater understanding of the pathway towards referral and diagnosis, the current exploratory study sought to examine clinical information from the electronic health records of all infants, children, and adolescents who were seen by a provider for an initial diagnostic visit in a specialty diagnostic clinic within a one-year period (September 12, 2019 – September 12, 2020). An array of child-related, family-related, and referring healthcare provider-related factors were examined as predictor variables to determine their association with match of referral for ASD and subsequent diagnosis of ASD, as well as to identify if there were specific factors that were consistently associated with early identification and referral of children at or under the age of three (younger than 47 months). Results indicated that 19 diagnostic (developmental, social-emotional, and medical disorders), demographic (race/ethnicity, sex, age, and geographic location), historical (caregiver-reported concerns), and

professional licensure (provider practice type) factors and factor combinations predicted match of referral and diagnosis with ASD, while 35 separate diagnostic (developmental and social-emotional disorders), service provision (early and therapeutic supports), historical (caregiver-reported concerns), professional licensure (provider practice and role type), and clinical practice (screening conduction) factors and factor combinations were associated with timeliness of referral. These findings suggest important considerations for clinical practice and training, as well as highlight future research directions.

Chapter 1

Literature Review

The purpose of this chapter is to provide a comprehensive review of the research literature. First, the population of interest is described, and the diagnostic criteria, associated features, and prevalence rates of autism spectrum disorder (ASD) are outlined. Next, information regarding the importance of early identification of ASD is highlighted, and the comprehensive identification process for ASD and its associated challenges are delineated. Then, research is discussed which identifies factors associated with the pathway toward referral for ASD and subsequent diagnosis of ASD. Finally, limitations and recommendations for future research are presented, and an overview of the current study and associated research questions is provided.

Diagnostic Criteria and Features of ASD

Overview

ASD is a lifelong neurodevelopmental disorder characterized by core impairments in social communication, social interaction, and restrictive and repetitive patterns of behavior (American Psychiatric Association, 2013). According to the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5), several criteria must be met to qualify for a diagnosis of ASD. First, an individual must exhibit persistent deficits in social communication and social interaction across multiple contexts either currently or by developmental history. These include challenges with social-emotional reciprocity (such as abnormal social approach, failure to sustain back-and-forth conversation, reduced sharing of interests and emotions, and/or failure to respond to social interactions), nonverbal communicative behaviors used for social interaction (such as poorly integrated verbal and nonverbal communication, abnormalities with eye contact, and/or

lack of understanding and use of gestures, facial expressions, and body language), and developing, maintaining, and understanding social relationships (such as inability to adjust one's behavior to align with social contexts, failure to engage in play with peers, and/or the absence of interest in peer interactions). Second, an individual must exhibit restricted and repetitive patterns of behavior, interests, or activities either currently or by historical report. These may include stereotyped or repetitive motor movements, object use, or speech (such as motor stereotypy, lining up of objects, idiosyncratic phrases, and/or echolalia), ritualized patterns of behavior or inflexible adherence to routines (such as challenges with transitions, distress at small changes in routine, and/or rigid thinking patterns), restricted or fixated interests that are abnormal in intensity or focus (such as a strong preoccupation with unusual objects and/or excessively circumscribed interests), as well as hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (such as indifference to pain or changes in temperature, adverse reactions to particular textures or sounds, visual fascination with lights or movement, and/or excessive smelling or touching of objects). Third, these symptoms must be present in the early developmental period but may not fully manifest until social demands exceed an individual's ability level. Fourth, these symptoms must cause clinically significant impairment in one's current social, educational, or occupational functioning. Finally, alternative diagnostic explanations must be ruled out (such as intellectual disability (ID), global developmental delay, and social communication disorder). In addition to the previously mentioned diagnostic criteria for ASD, the severity of ASD symptoms is also reported. These severity levels detail the extent of impairment and the amount of support that an individual will require based on current challenges with social communication, social interaction, and restricted and repetitive behaviors.

Although symptoms are neurologically based and common among individuals diagnosed with ASD, the behavioral presentation of symptoms, extent of functional impairment, required levels of support, and disorder prognoses are diverse and vary significantly across individuals (American Psychiatric Association, 2013; Hyman et al., 2020).

Social Communication and Interaction

Impairments in social communication and social interaction may present differently in individuals of varied ages. For young children, these impairments may include difficulties with response to name, joint attention, and the use of coordinated eye contact, facial expressions, body postures, or gestures within the social context. Imaginative play is often markedly impaired, and infants and toddlers may not engage in simple imitation activities or routines (Woods & Wetherby, 2003). Further, research has identified that toddlers with ASD use significantly less pointing, showing of objects, positive affect paired with eye gaze, motor imitation, and orientation to social stimuli than children who are typically developing or have other developmental disabilities (Dawson, 1990; Rogers et al., 2003; Smith & Bryson, 1994; Stone et al., 1997; Wetherby et al., 2004; Wetherby et al., 2007; Zwaigenbaum et al., 2009; Zwaigenbaum et al., 2013; Zwaigenbaum et al., 2015). As children age, they may lack interest in developing friendships with others and struggle to maintain peer relationships. As individuals enter adolescence and young adulthood, they may desire peer and romantic relationships but experience challenges with understanding the intricacies of friendship, the reciprocal exchange necessary for conversation, and how to engage in shared enjoyment with others. Challenges with theory of mind (or the ability to understand how oneself and others have independent mental states related to thoughts, emotions, and behaviors) are common across development for

individuals with ASD, and individuals with ASD commonly experience difficulty with comprehending and understanding the individual perspectives of others (Baron-Cohen et al., 1985).

Stereotyped, Restricted, and Repetitive Behaviors

Stereotyped, restricted, and repetitive behaviors, routines, or interests are another defining feature of ASD. Children with ASD may have inflexible schedules or routines (such as a lengthy and detailed morning ritual) and often struggle with small changes to their routine or environment (such as changing utensils or dishware used for meals). Restricted interests or patterns of behavior may be intense and extremely focused, including activities such as the lining up of objects or excessive interests in certain topical areas. Frequently, individuals demonstrate an interest in particular parts of objects (such as the wheels of a toy vehicle or buttons on a phone) and have an intense preoccupation with certain objects or interests (such as a paper clip or set of particular toys). Additionally, many children with ASD become fascinated with particular motor movements, visual patterns, object textures, and sound (American Psychiatric Association, 2013; Kim & Lord, 2010). While these restrictive and repetitive behaviors, rituals, and interests can be observed throughout development, they generally decrease with age (Esbensen et al., 2009).

ASD vs. Other Similar Disorders and Comorbidity

Although ASD is a uniquely recognized disorder, it shares characteristics with other neurodevelopmental and psychological disorders that present during the developmental period. Additionally, various disorders are comorbid with a diagnosis of ASD. The DSM-5 diagnostic criteria for ASD include specifiers for associated features of the disorder, which provide an

opportunity to identify other disorders that may be present with the diagnosis of ASD. These specifiers include accompanying intellectual impairment or language impairment, co-occurring medical or genetic conditions (such as fragile X syndrome or Rett syndrome), associated neurodevelopmental, mental, or behavioral disorders, and catatonic behavior (American Psychiatric Association, 2013; Gardner et al., 2016). Approximately 33% of children with ASD are diagnosed with co-occurring ID, and individuals diagnosed with both ASD and ID demonstrate greater impairments in adaptive behaviors, social skills, challenging behaviors, and co-occurring mental health disorders than those with ASD or ID alone (Centers for Disease Control and Prevention, 2020; Hyman et al. 2020; Matson & Shoemaker, 2009). Young children with diagnoses of both ASD and ID have also been found to experience more challenges with developing social competence than those with ASD alone (Bennett et al., 2014). Additionally, individuals with ASD commonly demonstrate adaptive skill challenges with socialization and communication abilities, although the adaptive behavior profiles of individuals with the disorder are highly variable (Carter et al., 1998; Gardner et al., 2016). As with cognitive and adaptive functioning impairments, the language profiles of individuals with ASD vary significantly. Absent, delayed, or atypical language development are some of the first warning signs for ASD, and approximately 30% of individuals with the disorder remain nonverbal throughout the life course (Tager-Flusberg & Kasari, 2013). Additionally, many children with ASD exhibit further speech and communication challenges, including echolalia, atypical vocal pitch or tone of voice, narrow conversational topics of interest, and poor nonverbal communication skills (U.S. Department of Health and Human Services, Health, and National Institute on Deafness and Other Communication Disorders, 2014). Further, young children with diagnoses of ASD and language

impairment demonstrate more social challenges than those diagnosed with ASD alone (Bennett et al., 2014). Regarding associated disorders and conditions, individuals with ASD commonly present with challenging behaviors (such as self-injury, physical aggression toward others, and/or tantrum behavior), feeding and sleeping difficulties, seizure disorders, hyperactivity, impulsivity, and attentional challenges, as well as are at increased risk for developing anxiety and mood disorders (American Psychiatric Association, 2013; Hyman et al., 2020; Leyfer et al., 2006; van Steensel et al., 2011). According to research, the best indicators of ASD prognosis include cognitive ability, joint attention skills by the age of four, and functional spoken language by the age of five (Johnson & Myers, 2007).

Prevalence of ASD

Historically, it was believed that there were approximately four to five cases of ASD for every 10,000 people (Lotter, 1966; Wing & Gould, 1979). However, prevalence rates have markedly increased over time, with one in every 150 children being estimated to have ASD in 2000 and one in every 88 children in 2010 (Centers for Disease Control and Prevention, 2007; Centers for Disease Control and Prevention, 2012). Currently, the Centers for Disease Control and Prevention (CDC) estimates that approximately one in every 54 children in the United States have ASD, which accounts for approximately 1.85% of children being identified with the disorder (Centers for Disease Control and Prevention, 2020). According to recent studies, the prevalence of ASD educational classification has increased faster than any other Individuals with Disabilities Education Improvement Act (IDEIA) disability category (Newschaffer et al., 2005), and rising prevalence of the disorder is considered a public health crisis (Dingfelder & Mandell, 2011). ASD is reported to occur in all racial, ethnic, and socioeconomic groups (Baio et al.,

2018; Fombonne et al., 2001), and rates of diagnosis are 4.3 times higher for males than females (Centers for Disease Control and Prevention, 2020). Prevalence estimates are approximately identical for children who are Non-Hispanic/Latino White/Caucasian (Non-His/Lat W/C), Non-Hispanic/Latino Black/African American (Non-His/Lat B/AA), and Non-Hispanic/Latino Asian/Pacific Islander (Non-His/Lat A/PI), but slightly lower for children who are Hispanic/Latino (His/Lat; Centers for Disease Control and Prevention, 2020). The rate of ASD in siblings is much higher than the rate in the general public, and twin studies demonstrate significantly higher concordance rates for identical twins than non-identical twins (Tick et al., 2016). Studies indicate 98% concordance in identical twin pairs and 53-67% concordance in non-identical twin pairs, as well as heritability estimates between 64-91% (Nordenbaek et al., 2014; Tick et al., 2016).

Although it is not fully clear why the prevalence of ASD has continued to increase with time, some potential reasons have been proposed. In part, increases in prevalence may be due to changes in conceptualization of ASD as a spectrum of disorders and restructuring of the DSM-5 criteria necessary for diagnosis, as well as growing public awareness of the disorder and its associated characteristics among parents, families, healthcare professionals, and educators. Additionally, with the development of specialized assessment measures for ASD and recommendations for universal disorder-specific screening, individuals previously misdiagnosed with other disorders (such as ID or comorbid genetic conditions) may now be identified with the appropriate classification (Centers for Disease Control and Prevention, 2018; Centers for Disease Control and Prevention, 2020; Hyman et al., 2020). Furthermore, research suggests that additional biological factors (such as being born prematurely, of low birth weight, or to older

mothers and fathers) may also contribute to true increases in the total number of cases of ASD (Durkin et al., 2008; Hyman et al., 2020; Schendel & Bhasin, 2008).

Early Signs and Symptoms of ASD

Early signs of ASD can manifest during the developmental period of six to 18 months (Bhat et al., 2011), and the communication, social, and restrictive and repetitive behaviors characteristic of the disorder typically become apparent between one and two years of age (Courchesne et al., 2007; Kozlowski et al., 2011; Ozonoff et al., 2008; Pierce et al., 2011; Watt et al., 2008). Variability exists in the types of concerns that are recalled and reported by parents, although concerns are frequently identified regarding delayed speech and language development, lack of response to name, behavioral reactivity, abnormal response to social and play situations, disruption in motor development, and challenges with sleep and feeding (Werner & Dawson, 2005; Woods & Wetherby, 2003; Young et al., 2003; Zwaigenbaum et al., 2009; Zwaigenbaum et al., 2013; Zwaigenbaum et al., 2015). Further, a regression in language or social skills is reported for approximately 25% of children with ASD, which most frequently occurs between 18 and 24 months of age (Barbaresi, 2016; Bradley et al., 2016). According to both retrospective and prospective behavioral research studies, impairments present in young children with ASD can also be seen in 12-month to 18-month old infants later diagnosed with the disorder. These impairments, which are able to be distinguished in infants who are later diagnosed with ASD from other at-risk infants, include potential delays in the following areas: visual (including atypical visual tracking, visual fixation on objects, and/or abnormal orientation to people and faces), motor (including decreased or atypical motor movements and/or delayed fine or gross motor skills), play (including delay in imaginary play, limited play with toys, and/or repetitive

actions with toys), social communication (including atypical eye gaze, abnormal orientation to name, lack of social interest, reduced display of positive affect and social smiling, and/or decreased initiation of joint attention through pointing or showing of objects), speech and language (including delay in babbling, language expression and comprehension, and/or use of gestures), and overall cognitive development (including slow acquisition of new skills)(Hutman et al., 2010; Kozlowski et al., 2011; Ozonoff et al., 2010; Rozga et al., 2011; Yoder et al., 2009; Zwaigenbaum et al., 2009; Zwaigenbaum et al., 2013; Zwaigenbaum et al., 2015). Although some children later diagnosed with ASD show signs of atypical development around the time of their first birthday (Palomo et al., 2006), children with later onset typically demonstrate developmental impairments by 18 to 24 months of age (Bryson et al., 2007; Landa et al., 2007; Landa et al., 2012; Wetherby et al., 2004).

To assist caregivers and professionals in identifying early signs of ASD, developmental milestones should be consistently tracked, and concerns should be raised whenever impairments or delays are identified (Autism Speaks, 2019; Centers for Disease Control and Prevention, 2019). By the age of six months, concerns should be noted if a child is not engaging in social smiling or facial expressions, as well as if the child is demonstrating minimal to no eye contact. By nine months of age, families and providers should become concerned if a child is engaging in little to no back-and-forth sharing of vocalizations, social smiles, or facial expressions, and concerned by the age of 12 months if the child engages in little to no verbal babbling or does not respond to his or her name. Concerns should be raised if a child does not engage in back-and-forth gestures (such as pointing, showing, reaching, or waving) by 14 months, uses few to no spoken words by 16 months, does not engage in pretend play by 18 months, or uses few to no

meaningful two-word phrases (not including imitation or repetition of phrases) by 24 months. At all ages, caregivers and providers should become concerned if a child loses any previously acquired language or social skills, avoids eye contact, has a persistent preference to be alone, experiences challenges with understanding and discussing one's own emotions or those of others, has delayed speech and language development, engages in immediate or delayed echolalia, demonstrates resistance to minor changes in routine or environment, provides unrelated responses to questions, engages in repetitive motor behaviors (such as flapping hands, spinning, or rocking), experiences unusual and/or intense reactions to sensory components of the environment (such as sound, smell, taste, touch, or sight), or has restricted and obsessive topical interests (Autism Speaks, 2019; Centers for Disease Control and Prevention, 2019).

Delays in Identification of ASD

Although early identification and diagnosis of ASD are major public health goals and objectives of *Healthy People 2020* (U.S. Department of Health and Human Services, 2020), the age of initial diagnosis has changed little over the course of time (Centers for Disease Control and Prevention, 2020). Research has shown that a reliable, valid, and stable diagnosis of ASD can be made well before the age of two (Centers for Disease Control and Prevention, 2014; Guthrie et al., 2013; Kleinman et al., 2008). However, despite the fact that ASD can be diagnosed prior to two years of age, epidemiological analyses indicate that the average age of initial diagnosis in the United States is four years and three months, and 26% of children who meet diagnostic criteria for ASD have not received an official diagnosis by eight years of age (Centers for Disease Control and Prevention, 2020). Based on data gathered through population-level surveillance via the Autism and Developmental Disabilities Monitoring (ADDM) Network

(Centers for Disease Control and Prevention, 2020), as well as information compiled through metanalytic review (Daniels & Mandell, 2014), Non-His/Lat B/AA and His/Lat children with ASD have been shown to be evaluated at later ages than Non-His/Lat W/C children, as well as more likely to have a co-occurring diagnosis of ID. Through these studies, Non-His/Lat B/AA children with ID and ASD have been shown to receive diagnoses at later median ages than Non-His/Lat W/C children with ID and ASD, which may contribute to limited opportunities for accessing early intervention services and improvements in overall quality of life. Furthermore, within these studies, children who spoke a non-English primary language or came from a household in which English was not the primary spoken language were shown to experience further delays in diagnostic identification of ASD, especially among His/Lat children (Centers for Disease Control and Prevention, 2020; Daniels & Mandell, 2014). The majority of children with ASD have documented developmental concerns before three years of age, but significant lags exist between time of initial concern and time of developmental evaluation. Based on national data from the ADDM Network representing children who were eight years of age in 2014 (Baio et al., 2018) and 2016 (Centers for Disease Control and Prevention, 2020), only 43% of children identified with ASD had received a comprehensive diagnostic evaluation by three years of age, *even through approximately 85% of children had developmental concerns by the age of three*. Further, within the state of Wisconsin, approximately 90% of children identified with ASD had concerns noted by three years of age, but only 50% had received a developmental evaluation by that time (Baio et al., 2018; Centers for Disease Control and Prevention, 2020). This lag between time of initial developmental concern and time of developmental evaluation greatly influences the age at which children with ASD are eligible to begin participating in

intervention programs and accessing necessary services, which can significantly impact the long-term developmental trajectories of these individuals. Despite research indicating the critical need for early identification and intervention for ASD to promote positive developmental outcomes, these statistics raise significant concerns regarding delays in referral and diagnosis.

Impact of ASD

The impact of having a child with ASD on caregivers, siblings, and greater society is considerable. Parents and caregivers of children with ASD self-report significantly more stress than those of children who are typically developing or have other developmental delays or disabilities (Rao & Beidel, 2009; Schieve et al., 2011), which often begins long before a formal diagnosis has been provided (Karst & Vaughan Van Hecke, 2012). The lifelong burden placed on parents and caregivers of individuals with ASD can negatively impact parental efficacy and the perceived ability to effectively parent, lead to general decreases in overall well-being, and contribute to increased mental and physical health concerns (Ekas et al., 2010; Gau et al., 2011). Further, increases in parenting distress and conflict can contribute to higher rates of divorce for parents of children with ASD and lead to significant practical challenges, including continuous time pressure, financial burden and strain, fewer career opportunities, constant self-advocacy, and difficulty accessing necessary healthcare services (Lord & Bishop, 2010; Woodgate et al., 2008). In addition to caregivers, siblings of children with ASD can also experience challenges. According to research studies, most individuals self-report having relatively positive relationships with their sibling with ASD. However, these siblings also indicate having received decreased parental and familial attention, encountered difficulties with communicating and socially interacting with their sibling with ASD, and experienced embarrassment in public

locations (Karst & Vaughan Van Hecke, 2012; Rivers & Stoneman, 2003). Although the impact of having a child or sibling with ASD can be mitigated through the application of coping strategies and utilization of social support, the ability to effectively employ these techniques can be limited due to practical constraints and financial demands (Karst & Vaughan Van Hecke, 2012).

In addition to the impact of ASD on family members, there are significant economic and societal costs associated with healthcare, educational, and community supports for these individuals. With the frequent requirement for life-long care and support across these areas, these needs can lead to significant costs for the individual diagnosed with ASD, immediate and/or extended family members, private and/or public insurance agencies, federal and/or state financial assistance programs, and society at large. Currently, the estimated lifetime cost of supporting an individual with ASD in the United States is $1.4 million, and support for an individual with ASD and ID is $2.4 million (Rogge & Janssen, 2019). Regarding healthcare, reports of service utilization and expenditure patterns indicate that individuals with ASD have significantly higher medical costs than the general population (Croen et al., 2006; Ganz, 2007), as well as that these costs steadily increase over the life course (Cidav et al., 2013) and are typically greater than expenditures for individuals with other mental health conditions (Leslie & Martin, 2007). Regarding therapeutic treatment, metanalytic research also highlights substantial costs for early intensive behavioral intervention (EIBI) programs, with yearly estimates ranging from $40,000 to $60,000 per child with ASD (Rogge & Janssen, 2019). However, costs for therapeutic services appear to be highest during early childhood and gradually decrease with maturation, and

participation in EIBI programs appear to produce significant cost savings in the form of future educational and community supports for individuals with ASD (Peters-Scheffer et al., 2012).

Importance of Early Identification for ASD

Early detection can lead to early clinical diagnosis, which can further lead to early intervention opportunities for children with ASD and help to prevent secondary effects of atypical development. Early intervention (especially when implemented before three years of age) has been shown to result in significantly improved outcomes compared to intervention implemented later in life (Dawson, 2008; Dawson et al., 2009), with research indicating that early intervention for children with ASD can greatly improve social communication, language, daily living skills, and cognitive functioning (Reichow et al., 2012; Rogers & Vismara, 2008; Zwaigenbaum et al., 2015). Based on studies which compared children who did and did not receive early interventions during childhood, children with ASD who were provided with early and ongoing intervention services demonstrated enhanced language and social interaction outcomes compared to those who did not receive such services, suggesting that participation in EIBI programs is crucial for optimizing long-term developmental outcomes (Fein et al., 2013; Harris & Handleman, 2000; Reichow et al., 2012). Further, participation in EIBI has been shown to significantly decrease the presence of challenging and maladaptive secondary symptoms (such as self-injurious behavior, aggression, and tantrums), prevent future development of co-morbid mental health difficulties (including depression and anxiety), contribute to family cost savings across developmental ages, empower caregivers with tools and strategies to address symptoms at the earliest point in time, and improve overall well-being of families (Durand et al., 2013; Emerson et al., 2016; Koegel et al., 2014; Rogers & Vismara, 2008). Through the promotion of

early surveillance, screening, diagnostic assessment, and intervention services, young children with ASD can make significant developmental gains in the areas of social, emotional, cognitive, and behavioral functioning (Dawson et al., 2009; Eaves & Ho, 1996). By identifying children with ASD as soon as possible during development, effective and appropriate behavioral treatment programs can be developed and implemented to target early behavioral change, and policies can be created to reduce disparities and assist with service planning needs. Further, by providing children access to early treatments that are effective at improving impairments associated with ASD, studies of healthcare practice suggest that the need for future disability-related supports and the associated cost for special education services in later childhood may significantly decrease (American Academy of Pediatrics, Committee on Children with Disabilities, 2006). Early detection and evaluation of ASD among young children continue to be important public health goals due to evidence linking early services with significantly improved outcomes (Reichow et al., 2018; Rogers et al., 2019; U.S. Department of Health and Human Services, 2020), suggesting that early and timely identification of ASD has never been more important.

Comprehensive Identification Process for ASD

A comprehensive identification process for ASD includes universal developmental and ASD surveillance and screening, developmental and ASD screening when concerns are raised during the surveillance process, and clinical diagnostic evaluation when there is a concerning screening result. Developmental evaluation should assess developmental concerns related to ASD, confirm or rule out diagnoses, and identify targeted areas for linking assessment findings

to intervention (Gardner et al., 2016). Engagement in all steps of the identification process is key to the delivery of appropriate services and supports for children with ASD and their families.

Universal ASD Surveillance and Screening

Universal developmental and ASD surveillance and screening are recommended strategies for promoting early identification and intervention for developmental disabilities, and the healthcare setting has been identified as an important location for these procedures to occur (Hyman et al., 2020; Lipkin et al., 2020b). Universal surveillance, or the ongoing process of recognizing all children who may be at risk for developmental delays and ASD, is recommended during all healthcare visits until a child is at least five years of age (Bright Futures Steering Committee & Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2006; Gardner et al., 2016; Lipkin et al., 2020b). If concerns arise during the universal surveillance process, regardless of age, follow-up screening should immediately be conducted to clarify risk. Universal screening, or the use of standardized measures to identify and refine risk for developmental delays and ASD, is recommended for all children during specified well-child visits. The AAP has recommended that broad developmental screening be conducted for all children at 9, 18, and 30 months of age, ASD-specific screening be completed for all children at 18 and 24 months of age, follow-up clinic visits be scheduled when family or practitioner concerns remain after a negative screening, and referrals be made for a clinical diagnostic evaluation after a positive screening or in the presence of two or more ASD risk factors (Baird et al., 2001; Charman et al., 2016; Hyman et al., 2020; Johnson & Myers, 2007; Lipkin et al., 2020b). To effectively conduct universal developmental and ASD surveillance and screening, individuals charged with this task, including pediatric healthcare providers, must have

sufficient knowledge of typical and atypical child development, as well as an understanding of measures with which to screen for the early symptoms and warning signs of ASD.

To be most effective, best practice guidelines suggest that comprehensive developmental and ASD surveillance should include attending to concerns and questions of the family, gathering information about the child's overall development, directly observing the child's behavior and current skills, determining the presence of risk factors (such as genetic, environmental, and/or demographic variables) and protective factors (such as supportive family factors, financial stability, and/or opportunities to engage with peers), and recording all surveillance and planned follow-up activities in the child's records (Bright Futures Steering Committee & Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2006; Hagan et al., 2017; Hyman et al., 2020). Surveillance for ASD includes asking questions about familial history of ASD (such as whether parents, siblings, or other family members have previously received diagnoses), inquiring about symptoms related to ASD (including questions about the child's language or language approximations, nonverbal social communication, ability to engage in reciprocal social interaction, and imaginary play skills), examining the child's achievement of developmental skills related to ASD (such as direct observation of the child's response to name, joint attention, eye contact, and shared enjoyment with the provider), and establishing a follow-up plan of care (including screening as an immediate consequence) based on information gathered by the provider and concerns raised by the family (Autism Speaks, 2019; Johnson & Myers, 2007). To assist with this process of identifying early signs of ASD, developmental "red flag" and "warning sign" guidelines have been published, including the *Learn the Signs. Act Early.* (Centers for Disease Control and

Prevention, 2019) public health campaign and the *First Concerns to Action Tool Kit* (Autism Speaks, n.d.b) and *First Concern to Action Roadmap* (Autism Speaks, n.d.a) developmental resources.

Screening, or the prospective identification of conditions through the application of specific testing, involves administration of standardized screening instruments to a large group of individuals to detect who may be at particular risk for a disorder from an otherwise healthy population (Baird et al., 2001; Hagan et al., 2017). Screening instruments do not determine diagnostic decisions, but instead suggest level of potential risk. Developmental and ASD screening are built on the notion that early identification and diagnosis of previously undetected difficulties will result in enhanced outcomes for individuals with developmental delays and disorders, and the importance of early and regular screening for ASD has been emphasized by numerous professional healthcare organizations (Ibanez et al., 2014; Hagan et al., 2017; Johnson & Myers, 2007). However, according to studies of healthcare practice, while the use of developmental screening measures by pediatric healthcare providers has tripled from 2002 to 2016, only 63% of providers in 2016 reported utilizing these recommended practices (Lipkin et al., 2020a). In addition to screening guidelines outlined by the AAP (Hyman et al., 2020; Lipkin et al., 2020b), the American Academy of Neurology and the Child Neurology Society recommend that pediatric providers engage in routine developmental surveillance with all children and conduct follow-up screening for ASD when concerns arise regarding atypical development (Filipek et al., 2000), and the American Academy of Child and Adolescent Psychiatry suggests that pediatric providers routinely include measures examining ASD symptomatology in the developmental and psychiatric assessment of all children (Volkmar et al.,

2014a). Research indicates that routine use of developmental and ASD screening can increase practitioner knowledge about the early markers and warning signs of ASD, reduce bias in referrals for further clinical evaluation, and lower the age of initial ASD diagnosis (Charman et al., 2001; Oosterling et al., 2010; Warren et al., 2009). Gains in acceptance and widespread use of these practices are somewhat improving, but efforts are needed to further improve adoption and implementation of these recommendations for screening of all children and screening for ASD specifically.

Types of Screening Tools. Due to the importance of early identification and individualized intervention for young children with ASD, various screening measures have been developed. By incorporating screening tools into practice, professionals can better identify children who may be at-risk for developmental delays and ASD and refer these individuals for additional screening and diagnostic evaluation services as necessary (Campbell et al., 2016; Meisels, 1985). These approaches include Level 1 broad developmental screening measures, Level 1 ASD disorder-specific screening measures, and Level 2 ASD disorder-specific screening measures.

Screening measures can vary across several different dimensions, which can impact their suitability for different settings (Zwaigenbaum & Stone, 2006). When considering screening procedures, these different dimensions include the level, breadth, and format of screening (Robins & Dumont-Mathieu, 2006). With multiple factors to contemplate, the selection of screening instruments must be guided by considerations such as the type of information desired, characteristics of the child and family, demands of the screening procedures, psychometric

properties of the screening tools, and background and training of individuals who will administer the screening measures (Ibanez et al., 2014).

Level of Screening. Two levels of screening instruments can be utilized: Level 1 and Level 2. Level 1 (universal) screening measures (specified in the upcoming section) are used to identify children at-risk within the broader population. These measures are typically administered to all children within a given setting of interest (such as a primary care practice, school, daycare, early childhood learning center, or early intervention center) regardless of whether developmental concerns are present to allow for rapid identification of individuals who demonstrate some or all symptoms of ASD (Ibanez et al., 2014; Livanis & Mouzakitis, 2010). Universal screeners involve a brief survey-like format, and most children evaluated through this type of procedure are not at-risk for developmental delays or disabilities. Alternately, Level 2 screening tools (also specified in the next section) are used to detect risk for ASD among individuals already considered to be at increased risk for the disorder. These individuals may be the younger siblings of children already diagnosed with ASD or have been referred for a variety of neurodevelopmental concerns (Robins & Dumont-Mathieu, 2006). These Level 2 screening tools (which are at times also used as Level 1 screening measures) often involve both family report and clinical observation, and are more commonly used in community settings that serve children with a variety of developmental challenges (such as child-find agencies, early intervention programs, or diagnostic evaluation centers).

Breadth of Screening. In addition to the level of screening, there is also variability in the breadth or scope of screening tools that can be administered, as both broad developmental screening and disorder-specific screeners are available. Broad developmental screening targets

identification of a range of developmental difficulties, and these measures are considered both cost-effective and efficient. Furthermore, broad screening instruments detect the presence of developmental delays rather than specific disorders and can be used to identify a wide range of developmental risk factors for infants, toddlers, and young children. In contrast, disorder-specific screening measures are utilized to examine symptomatology of a specific disorder (such as ASD, attention-deficit/hyperactivity disorder (ADHD), or ID) or class of disorders (such as anxiety disorders or mood disorders). These disorder-specific instruments are considered more sensitive (the percentage of people with the disorder being correctly identified as having the disorder) and specific (the percentage of people without the disorder being correctly identified as not having the disorder) than broader developmental screening tools (Robins & Dumont-Mathieu, 2006).

Format of Screening. Another dimension on which screening measures differ is their format, which may include informant report, observation, or direct interaction. Informant report screening measures, which generally rely on parental report, have the strength of drawing upon caregiver knowledge regarding the child's development over time and behavior within different contexts. However, because caregivers are not always aware of the typical progression toward developmental milestones and may hold biased viewpoints regarding their child's development, these types of screeners may be prone to reporting bias. Alternatively, observational screening measures that utilize ratings of behavior in the immediate context can be highly beneficial if experienced raters are available to examine a child's current abilities related to age-specific developmental norms and expectations. However, use of this screening is limited to trained experts and is further restricted to consideration of data gathered at only a single point in time. Finally, screening instruments involving structured interactions with children are also available.

These screeners provide raters with the opportunity to directly experience a child's interaction style and use of social communicative behaviors in real time, but their use tends to require significantly more training, and they are more time-intensive to administer than alternative options (Ibanez et al., 2014; Zwaigenbaum & Stone, 2006).

Level 1 Broad Developmental Screening. Several broad developmental screening measures can be used to identify children who are at-risk for a variety of developmental challenges that include ASD. These instruments generally target a range of developmental domains, including cognitive, language, communication, motor, social, adaptive, and behavioral skills (Ibanez et al., 2014). Through the use of broad developmental screening, providers can conduct follow-up screening or make referrals to evaluation clinics or early intervention centers if children are identified as being at-risk for a developmental delay or disorder. As such, these instruments play a significant role in the early identification process (Campbell et al., 2016). Some examples of broad developmental screening measures include the *Ages and Stages Questionnaire, Third Edition* (ASQ-3; Bricker & Squires, 1999; Squires & Bricker, 2009), the *Parents' Evaluation of Developmental Status* (PEDS; Glascoe, 1998; Glascoe, 2003), and the *Communication and Symbolic Behavior Scales Developmental Profile* (CSBS DP; Wetherby & Prizant, 2002; Wetherby et al., 2008).

Level 1 Disorder-Specific ASD Screening. In order to identify behavioral symptoms characteristic of ASD, Level 1 disorder-specific ASD screening measures are available for use. Generally, these screeners assess for impairments in the core domains of social interaction, social communication, and restrictive and repetitive behaviors. Disorder-specific screening tools have been specifically developed to identify risk for ASD in samples of individuals from the general

population (Ibanez et al., 2014), and all screening measures focus on identifying risk in young children who are less than 36 months of age. Some Level 1 disorder-specific ASD screening measures include the *Modified Checklist for Autism Revised, with Follow-Up* (M-CHAT-R/F; Robins et al., 2001; Robins et al., 2009), the *Psychological Development Questionnaire-1* (PDQ-1; Zahorodny et al., 2018), the *First Year Inventory* (FYI; Reznick et al., 2007), and the *Early Screening of Autistic Traits Questionnaire* (ESAT; Dietz et al., 2006; Swinkels et al., 2006). If Level 1 universal screening identifies increased risk for ASD, then best practice guidelines recommend use of a Level 2 disorder-specific screening measure.

Level 2 Disorder-Specific ASD Screening Measures. Level 2 screening instruments have been designed to differentiate children at-risk for ASD from individuals who are at-risk for other developmental delays and disorders. These measures are typically used in referral settings for children who have already been identified as being at-risk for ASD or have been flagged by Level 1 screening procedures. Unlike Level 1 disorder-specific ASD screening instruments, Level 2 measures have been developed and validated for a broad range of ages. Additionally, Level 2 screeners are available in a variety of formats, including observational, caregiver report, and interactive types (Ibanez et al., 2014). Some examples of Level 2 instruments include the *Screening Tool for Autism in Toddlers* (STAT; Stone et al., 2000; Stone et al., 2004), the *Gilliam Autism Rating Scale – Second Edition* (GARS-2; Gilliam, 1995; Gilliam, 2006), the *Social Communication Questionnaire* (SCQ; Rutter et al., 2003), the *Systematic Observation of Red Flags* (SORF; Wetherby & Prizant, 2002; Wetherby et al., 2004), the *Autism Spectrum Screening Questionnaire* (ASSQ; Ehlers et al., 1999), and the *Autism Spectrum Rating Scale* (ASRS; Goldstein & Naglieri, 2010).

Overall, across both Level 1 and Level 2 screening measures, there are a wide variety and type that different providers can select to screen and monitor general developmental delays and concerns suggestive of ASD. The Centers for Disease Control and Prevention (2006) have recommended use of the ASQ-3 (Squires & Bricker, 2009) and PEDS (Glascoe, 1998; Glascoe, 2003) as broad developmental screening tools of choice, and the M-CHAT-R/F is the most commonly used and researched Level 1 screening measure for ASD in the general population (Campbell et al., 2016; Hyman et al., 2020). However, more broadly, there is not a universal consensus or administrative use of specific Level 1 or Level 2 screening measures.

Barriers Contributing to Challenges with Screening for ASD. Numerous barriers exist regarding use of screening to identify risk for ASD. Although pediatric primary care is often identified as the service setting where young children with ASD will be identified by professionals (Crais et al., 2014), studies suggest that many pediatric healthcare providers are not completing routine identification processes for ASD. Despite repeated calls and published recommendations by major healthcare organizations (including the AAP, American Academy of Neurology, Child Neurology Society, and American Academy of Child and Adolescent Psychiatry), compliance rates regarding conduction of routine screening are still relatively low. Using data from population-level surveys of family experiences and healthcare practices, about *two thirds* of parents with children between the ages of nine and 36 months had reported that their pediatric healthcare provider did not engage in surveillance or screening practices within the previous year (Hirai et al., 2018), and *only 43%* of pediatric providers had reported using formal screening measures when broad-based developmental surveillance indicated a concern for delayed or disordered development (Coury et al., 2017). Further, using survey methodology to

examine the healthcare practices of providers across six different states, Arunyanart et al. (2012) found that only 60% of pediatric care providers had conducted formal screening for ASD when children were 18 months of age and 50% when children were 24 months of age. Additionally, retrospective chart review research by Rea et al. (2019) found that less than half of children were screened for ASD at regular well-child medical appointments. Particularly concerning was additional evidence that M-CHAT-R/F screening at the 18-month appointment had the lowest rate of provider completion, which is essential in providing families with information at the earliest point of referral for diagnostic evaluation (Rea et al., 2019). Thus, although guidelines detail specific action steps and highlight the importance of screening, research suggests that consistently low levels of pediatric healthcare providers are engaging in recommended best practices for identifying ASD.

Even when providers appropriately participate in screening, high rates of screening do not automatically translate to earlier identification of ASD, as accuracy of screening practices and challenges with post-screening referral procedures have also been identified as barriers. Regarding accuracy of screening practices, guidelines indicate the importance of providers engaging in the full assessment process when risk for ASD is identified. Following a positive screen on Level 1 disorder-specific tools such as the M-CHAT-R (Robins et al., 2001; Robins et al., 2009), providers are recommended to immediately conduct the M-CHAT-R/F follow-up interview with caregivers to validate the positive screen and determine continued risk for ASD. However, even though studies suggest that completion of the follow-up interview is effective in reducing false positive screens and determining children who are truly at-risk, families of lower maternal education and diverse racial and ethnic backgrounds have been shown as having lower

follow-up interview completion rates (Khowaja et al., 2015), and providers have been reported to be inconsistently completing follow-up interviews with caregivers during appointments (Rea et al., 2019). This lack of consistent follow-up with interviews can exacerbate disparities in access to screening, especially when families experience economic challenges or have reduced understanding of child development (Khowaja et al., 2015). Research further suggests that healthcare providers commonly engage in inconsistent post-screening referral procedures. If positive screening is confirmed after completion of follow-up interviews, providers are encouraged to either complete Level 2 disorder-specific screening for ASD or refer families for a comprehensive diagnostic evaluation. However, professionals demonstrate little consistency in initiation of the referral process, as retrospective chart review studies indicate that relatively low rates of referrals are made to ASD specialists when concerns arise during screening, and families are commonly referred to a wide array of different providers for the same behaviors of concern (including psychologists, psychiatrists, speech-language pathologists, and audiologists). Additionally, when referrals are made, research suggests that they commonly lack coordination and follow-through, which can further complicate the ability to access services in a timely manner (Rea et al., 2019). Thus, although initial aspects of screening for ASD may take place, failure to engage in fully recommended practices or refer families to appropriate providers when concerns are identified may contribute to delays in accessing diagnostic evaluation and treatment services. However, a full understanding of these services and referral trajectories is limited within the literature. More information regarding service provision prior to ASD diagnosis, as well as when and how referral concerns are first identified (via records review), would greatly contribute to understanding of how providers engage in surveillance, monitoring, and referral

activities for ASD. Establishment of such predictors (which identify individuals who do and do not ultimately present with an ASD) would significantly aid overall understanding and inform pediatric practice.

Despite emphasis on early identification of ASD, additional barriers contribute to disparities in which children and families are able to benefit from access to disorder-specific screening. Although several psychometrically sound Level 1 disorder-specific screening tools have been developed for ASD, all measures focus on identifying risk in children younger than 36 months of age. While availability of tools for children at this age targets early identification of ASD, it limits the ability of providers to engage in disorder-specific screening with children who exceed this age range. Additionally, current disorder-specific screening measures for ASD are not particularly sensitive to children who have milder symptom expressions or average to above average cognitive abilities, which may lead to inaccurate detection and delayed referral of children who may truly be at-risk for ASD (Hyman et al., 2020; Sheldrick et al., 2017). Further, based on findings from a retrospective questionnaire survey of parents who had participated in a diagnostic evaluation for ASD, Donahue et al. (2019) found that Non-W/C parents endorsed fewer concerns regarding social behaviors, as well as restrictive and repetitive behaviors, than W/C parents during disorder-specific screening for ASD, suggesting that families of differing racial and ethnic backgrounds may perceive behaviors typically associated with ASD differently based on cultural or familial background. This, in turn, may impact the ability of healthcare providers to accurately identify children who may require further screening and evaluation services, as well as contribute to challenges with diagnostic delays and timely access to treatment. Therefore, factors of race, ethnicity, and socioeconomic status are additional features

that should be included in an analysis of records. These considerations would greatly assist in documenting the impact or differences that exist regarding provision of screening, monitoring, and referral services.

Healthcare providers cite time, decreased familiarity with tools, challenges with cost and reimbursement, lack of practitioner knowledge, implementation constraints, and limited confidence in accurately identifying symptoms and concerns for ASD as barriers to effectively utilizing disorder-specific screening measures in practice, with the predominant challenge being time (Anderson et al., 2003; Fenikile et al., 2015; Self et al., 2015). Because disorder-specific screening measures for ASD can be complex, many professionals fail to consistently use these screening instruments and instead prefer to utilize parental input or results from broad-based developmental screening tools. These alternative approaches are considered general, quick, readily interpretable, and able to detect a range of potential delays, which may be preferred by some who are responsible for making patient decisions (Guevara et al., 2013; Radecki et al., 2011). Furthermore, providers reference confusion regarding where to refer families, lack of trained professionals in evaluation and diagnosis of ASD, and lack of coordination and communication between service agencies involved in screening, diagnostic evaluation, and treatment as challenges to proper engagement in early identification practices for ASD (Association of Maternal and Child Health Programs, 2014). Although it has been recommended that disorder-specific screening for ASD be introduced into other locations to help address barriers that exist within the healthcare setting (Campbell et al., 2016), it has been challenging to readily adopt and implement these practices for a variety of reasons. Altogether, these findings suggest a significant need for improvement in current screening practices to promote timely and

early identification of ASD. As part of clinical case management within many specialty clinics for ASD, information regarding service provision, initial referral concerns, and the overall referral process is collected through intake surveys, questionnaires, and interviews. While a great deal could be learned about practices, procedures, and referral trajectories from information outlined in clinical health records, there is a limited amount of published information regarding data reported in this manner.

Diagnostic ASD Evaluation

If concerns are raised during the screening stage, the second step in identifying ASD involves administration of standardized assessments to confirm or rule-out a diagnosis. A diagnosis of ASD is made based on the presence of certain behaviors and the absence of others, as outlined in the DSM-5 (American Psychiatric Association, 2013). The "gold standard" for diagnostic evaluation of ASD involves the best-estimate clinical judgment of an interdisciplinary team or an individual professional (such as a psychologist or developmental pediatrician) with expertise in ASD and includes combined use of evidence-based diagnostic assessment tools, behavioral observation, and caregiver report. These measures require extensive knowledge of ASD to administer, interpret, and score, making them more expensive, time-consuming, and complex to use (Hampton & Strand, 2015). The core features of an empirically based assessment for ASD include caregiver report gathered through clinical interviews and questionnaires, ASD-specific diagnostic observation measures, standardized assessment of cognitive functioning, standardized assessment of speech and language abilities, and assessment of adaptive behavior functioning (Ozonoff et al., 2005). When making a determination of ASD, it is important to note that no single diagnostic instrument should be used in isolation. Instead, all measures should be

analyzed and interpreted in conjunction with an individual's medical and developmental history, caregiver report, additional standardized assessments, and clinical observation to formulate an accurate diagnosis. Training on these instruments and processes takes considerable time and supervision, and multiple professionals are needed to ensure ongoing and appropriate evaluation. Therefore, many of these comprehensive assessments are completed in clinical settings specializing in ASD assessment and intervention (Goin-Kochel et al., 2006; Wiggins et al., 2006). To greater understand predictors which are associated with individuals who are and are not identified with ASD, analysis of records from clinical visits should be initiated. This type of comprehensive record review would promote enhanced understanding of service provision and the referral process prior to diagnostic determinations and could significantly inform pediatric practice.

After a diagnostic evaluation for ASD has been conducted, the final step is presenting caregivers with results from the evaluation and providing recommendations for intervention and support. Following the diagnostic evaluation, a feedback session should be held to engage caregivers in active discussion about the assessment findings. Assessment results should be directly linked to all intervention and follow-up recommendations provided to the family. This information should be used to inform intervention planning by identifying areas of relative strength and weakness and targeting areas of difficulty with evidence-based treatment approaches (Volkmar et al., 2014b). Further, assessment information can be used to determine the amount of functional support that an individual will require to make gains throughout the intervention process (Gardner et al., 2016). To ensure that intervention techniques (such as applied behavior analysis, social skills intervention, psychological intervention, speech-language

therapy, physical therapy, and/or occupational therapy) are appropriately provided to individuals with ASD, the assessment process necessitates linked and individualized intervention planning and programming.

Barriers Contributing to Delayed ASD Diagnosis. Although it is possible to reliably diagnose children with ASD before the age of two (Centers for Disease Control and Prevention, 2014), current reports suggest that many children are not being identified until later in development (Centers for Disease Control and Prevention, 2020). As outlined in the literature, numerous barriers to timely diagnosis of ASD at or before three years of age exist. When beginning the process, families often experience significant wait periods between identification of first concern, referral to a diagnostic provider, conduction of the comprehensive developmental evaluation, and official delivery of the diagnosis. On average, studies suggest that families visit between four to five different providers throughout the assessment process and typically wait over one year between initiating evaluation services and receiving a diagnosis (Goin-Kochel et al., 2006; Wiggins et al., 2006). Furthermore, due to the lack of providers trained to diagnose and treat children with ASD, extensive wait times are associated with obtaining appointments (Kalb et al., 2012).

In addition to challenges with accessing diagnostic appointments, barriers also exist within the referral and diagnostic processes. Although some caregivers report suspicion of ASD early in their child's development, many are told not to be concerned about common features, such as delayed language development or self-isolating behaviors. Metanalytic and comprehensive literature review studies suggest that practitioners often attempt to reassure caregivers and recommend that families give development an opportunity to progress, which can

often discount the observations and concerns that they have experienced, contribute to poor service coordination between professionals, and delay referral for diagnostic evaluation (Elder et al., 2016). Within the evaluation process itself, children may not receive a diagnosis of ASD for various reasons. In many situations, a diagnosis may be straightforward and clear for individuals. However, a diagnosis of ASD may be more challenging for others given the presence or absence of particular behaviors, as well as the potential for comorbid neurodevelopmental, psychiatric, and behavioral disorders. Furthermore, because ASD is a spectrum disorder, the diagnosis is associated with a wide range of behavioral symptoms that can impair individuals to varying degrees and significantly change with time (Lord et al., 2014). For providers with less expertise in diagnosing ASD and understanding nuanced expressions of the disorder, population-based surveillance and survey studies suggest that children who present with fewer symptoms, less functional limitations, and lack of intellectual challenges may particularly experience delays in diagnosis (Durkin et al., 2017; Maenner et al., 2013; Mandell et al., 2002). Furthermore, inexperienced clinicians may gravitate toward diagnoses with better prognoses, as many professionals require a particular level of certainty before delivering a lifelong diagnosis of potential impairments.

Additionally, many families face barriers that can further impede the evaluation process for ASD. According to survey and metanalytic review studies, delays in diagnosis may be related to lack of knowledge about ASD and the healthcare system, stigma surrounding potential identification of a developmental disability, decreased access to quality healthcare services, challenges with understanding how health and education systems communicate and authorize services, increased levels of family stress and anxiety, and financial obstacles dependent on

insurance funding and coverage (Jimenez et al., 2012; Matson & Goldin, 2014; Wiggins et al., 2006; Zuckerman et al., 2013). Sociodemographic disparities in accessing timely diagnostic services are also present, particularly with respect to race/ethnicity and geographic location of families. Regarding racial and ethnic disparities in accessing services, self-report data and healthcare claims research suggest that Non-W/C caregivers report healthcare professionals not spending sufficient time with their children, listening carefully to their concerns, or making them feel like partners in the healthcare process, and additional evidence suggests that healthcare providers are more likely to diagnose developmental and behavioral disorders in Non-W/C children (as compared to W/C children) before eventually assigning a diagnosis of ASD (Mandell et al., 2007). Research also outlines that greater delays exist between reported initial concerns and time of diagnosis for Non-W/C children, suggesting that Non-W/C caregivers may face increased challenges with communicating concerns to providers, navigating systems, or gaining access to referrals and specialists (Jegatheesan, 2009; Sansosti et al., 2012; Zuckerman et al., 2014). These caregivers may also wait longer to convey concerns to healthcare providers, which may be due to cultural stigma, distrust of providers and systems of healthcare, and discouragement from their family or community (Burkett et al., 2015; Jegatheesan et al., 2010; Zuckerman et al., 2017). Furthermore, families may experience diagnostic delays due to geographic barriers. Particularly for families of low socioeconomic status or those living in rural areas, research suggests that significant shortages of healthcare providers for underserved geographic locations and populations may also contribute to disparities in access (Bishop-Fitzpatrick & Kind, 2017; Rosenberg et al., 2011; Tregnago & Cheak-Zamora, 2012). Many families do not have access to ASD specialists in local communities and are often required to

travel significant distances to access evaluation services, which can be particularly challenging for families with limited financial resources, reduced means of transportation, and cultural or linguistic barriers (Gresenz et al., 2006).

To alleviate challenges related to diagnostic delays, Zablotsky et al. (2014) recommend that increased numbers of providers receive specialized training in ASD, wait times be reduced for obtaining diagnostic appointments, provider-family communication and support for parental decision-making be enhanced, coordination of care be promoted, and scope of healthcare access and coverage be increased. Such changes may assist in improving overall continuity of care, preventing challenges related to navigation of healthcare systems, and providing families with access to timely and comprehensive diagnostic evaluation services for ASD (Zablotsky et al., 2014). However, this is an area of need that has long been established but historically and logistically difficult to achieve. Across the literature, a multitude of challenges have been outlined, including limited numbers of pediatric healthcare providers following published guidelines, delays in diagnosis due to missed appointments or delayed access to appointments, and a variety of racial, ethnic, and socioeconomic barriers that further complicate the issue. Examination of clinical health records could further delineate the referral and service trajectory which facilitates clinical evaluation, as well as lead to greater understanding of the assessment outcomes and diagnostic decisions that result from the clinical evaluation process.

Potential Settings for Early Identification of ASD

Healthcare Settings

Best practice recommendations from the AAP highlight that pediatric primary care providers should engage in developmental and ASD surveillance, Level 1 developmental

screening, and Level 1 ASD disorder-specific screening practices with all children in the healthcare setting (AAP et al., 2006; Hyman et al., 2020; Johnson & Myers, 2007), and the American Academy of Neurology, Child Neurology Society, and American Academy of Child and Adolescent Psychiatry specifically outline that pediatric healthcare providers should conduct surveillance and screening practices for ASD (Filipek et al., 2000; Volkmar et al., 2014a). Thus, regardless of concern, there has been clear and consistent guidance that pediatric healthcare providers should be engaging in best practice surveillance and screening practices with all young children at routine well-child visits. However, although pediatric primary care is most often identified as the service setting where young children with ASD will be identified by professionals (Crais et al., 2014; Hagan et al., 2017; Hyman et al., 2020), many pediatric healthcare providers are not engaging in routine and consistent identification practices for ASD (Arunyanart et al., 2012; Coury et al., 2017; Hirai et al., 2018), and significant delays continue to exist between initial caregiver-reported developmental concerns and time of official diagnosis (Baio et al., 2018; Centers for Disease Control and Prevention, 2020). Thus, to best promote early identification of children with ASD, other providers and agencies serving young children are significantly needed to play a critical role in early surveillance and screening practices. Educational providers and allied health professionals have been called upon to proactively participate in these efforts, and early childhood learning centers, preschools, and early intervention programs have been identified as potential settings for the implementation of surveillance and screening practices (Campbell et al., 2016). Therefore, to extend beyond the traditional healthcare setting, these practices must be incorporated into various service delivery settings. These locations may include Head Start and Early Head Start programs, childcare

settings, and early intervention programs, and screening administrators might include classroom teachers, educational assistants, administrative personnel, school psychologists, speech-language pathologists, or early intervention service providers. By extending beyond the traditional healthcare setting and training professionals outside of pediatric primary care to engage in surveillance and screening practices, overall rates of early detection and access to intervention services are likely to increase, which will greater support positive developmental outcomes for all children with ASD. However, to date, little information is known regarding the services that children have accessed prior to comprehensive evaluation for ASD, as well as whether pediatric healthcare providers have consistently identified and referred for concerns of ASD. Thus, gathering and summarizing this information from the point of diagnostic clinic referral would greatly assist in understanding the role that supplemental settings and service providers may play in identifying and referring young children for ASD.

Early Head Start and Head Start Settings

One potential setting where surveillance and screening practices may be extended is Early Head Start and Head Start programs. Early Head Start programs were designed to provide comprehensive child development and family support services to low-income pregnant women, infants, and toddlers under the age of three, and were created to promote healthy attachment between children and caregivers. Although Early Head Start programs vary state by state, they offer home-based services, center-based services, and family childcare services (Early Head Start, 2018). Similarly, Head Start programs were designed to support children's growth in positive learning environments through a variety of services, including those related to early learning, health and nutrition, and family well-being. Head Start programs promote school

readiness of children up to five years of age from low-income families by emphasizing the development of the whole child. Head Start is primarily offered as center-based or school-based services (Head Start, 2019). Delivered through 1,700 different agencies in local communities across the United States, Early Head Start and Head Start programs provide services to over one million children every year. Approximately 80% of individuals served by these programs are children between the ages of three and four years old, and about 20% of program enrollment is comprised of infants, toddlers, and pregnant women (Head Start, 2019). As part of programmatic and performance requirements, Early Head Start and Head Start programs are required to conduct broad-based developmental monitoring and screening activities with all enrolled children. By engaging in these practices, program staff and families are able to discuss developmental concerns, identify and document potential developmental delays, determine the need for additional evaluation, and access supplemental services and supports (Head Start, 2020). In addition to professional requirements that outline the importance of engaging in broad-based developmental surveillance and screening practices, preliminary research has also suggested that early care and education professionals (ECEPs) in Early Head Start and Head Start programs may be well-suited to participate in disorder-specific screening for ASD. In a study by Janvier et al. (2016), ECEPs in various Head Start programs were trained to administer the M-CHAT-R/F with parents of enrolled children, as well as asked to complete the SCQ for all children served in those settings. Results of the study suggested that implementation of early identification processes is possible within Head Start programs, ECEPs in these settings are capable of administering and completing screening measures specific to ASD, and access to disorder-specific screening in these environments may eliminate barriers to early identification.

However, there exists a need to more fully understand the practical feasibility of implementing disorder-specific screening for ASD in these settings, as well as to determine the acceptability of engaging in these activities based on ECEP and administrative report (Janvier et al., 2016). Furthermore, additional documentation is needed to determine how access to Early Head Start and/or Head Start services inform or predict eventual referral for and diagnosis of ASD. Summarizing these findings as part of clinical health data collection may inform outcomes and recommendations for Early Head Start and/or Head Start agencies regarding the role they may play in identifying ASD during early childhood.

Childcare Settings

Similar to Early Head Start and Head Start programs, childcare settings may be other environments in which professionals can implement early identification practices for ASD. Before beginning formalized education, young children may spend time in a variety of different childcare settings, including accredited (programs that are licensed by the state and voluntarily participate in an official review process performed by a nationally recognized external agency) and non-accredited (programs that are licensed by the state but choose not to participate in the external review process) center-based childcare, licensed and unlicensed home-based childcare, and in their own home with primary caregivers (Macy et al., 2014). In 2012, 12.5 million children aged zero to four years were enrolled in some form of childcare setting outside of the home, which accounted for over half of children under five years of age in the United States (Laughlin, 2013). Although providers in all childcare settings may not be equally prepared and equipped to engage in universal surveillance and screening activities to promote early identification of ASD, professionals in some community childcare settings may be well-suited

for the task. Particularly, ECEPs working in settings that are center-based and accredited by the National Association for the Education of Young Children (NAEYC) may be best prepared to engage in these practices. Within these settings, ECEPs have numerous opportunities to observe child development on a daily basis and compare individual children to other same-aged peers in a structured environment, as well as have received specialized education and training in typical child development (Branson et al., 2008). The NAEYC professional preparation standards outline the importance of using direct observation and validated assessment measures to evaluate children's strengths, progress, and needs, as well as to identify individuals with developmental delays or disabilities (National Association for the Education of Young Children, 2003). Furthermore, the NAEYC outlines developmental screening as best practice for all children enrolled in childcare programs (National Association for the Education of Young Children, 2018). In addition to professional standards outlining the role that ECEPs can play, a variety of studies have also suggested that childcare providers have the capacity to engage in early identification practices for ASD. Within these studies, ECEPs demonstrated high agreement with parents in retrospectively identifying symptoms associated with ASD for children aged 12 to 24 months (Larsen et al., 2018), as well as highlighted the importance of incorporating both ECEP and parent reports to promote early detection of ASD (Dereu et al., 2012). However, research also indicates that few ECEPs are actually engaging in surveillance and screening activities in practice, as well as outlines that many providers do not view monitoring and screening children for the purposes of identifying risk for developmental delays and disabilities within the scope of their practice (Boh & Johnson, 2018; Branson & Bingham, 2017; Chodron et al., 2019). Therefore, significant needs exist for further training and support in these areas, as well as

dissemination of additional information regarding the importance of early identification processes for ASD in community childcare settings and the role these settings may play in referring children who are at-risk for more comprehensive assessments.

Early Intervention Settings

Early intervention programs are yet another setting where early identification practices for ASD may be implemented. Under the IDEA (2004), federal funding is allocated for early intervention services to children with significant developmental concerns or delays. In particular, Part C of IDEIA provides early intervention services for children from birth to three years of age with diagnosed physical or cognitive conditions that may result in developmental delays, who meet a state-determined level of significant developmental delay, or (in some states) who have significant likelihood for negative developmental impacts (Danaher et al., 2006). On average, young children are referred to early intervention programs around 13 months of age and begin receiving services around 16 months of age (Bailey et al., 2004). Approximately 377,896 infants and toddlers are served under Part C of IDEIA, which represents an estimated 3.1% of the total population of children within this age range in the United States (U.S. Department of Education, 2018). Unless an infant or toddler has been diagnosed with a condition associated with high probability for developmental delays, specific developmental concerns or delays must be identified before children can participate in early intervention services. Through developmental surveillance efforts in the healthcare and community settings and/or mandated state-level Child Find programs, children who may be eligible for early intervention services are identified and referred. Once referred to early intervention, programs are required to assess a child's overall development and determine whether they are eligible for Part C early intervention services. If the

child qualifies after participation in this process, an Individualized Family Service Plan (IFSP) is created to outline provided supports based on the child's needs, and the child is officially entered into Part C early intervention services (Barger et al., 2018). Although some components of early intervention services are federally mandated, individual states vary in how systems are structured, the extent of within-state variation in county and/or local programs, service eligibility criteria, models of intake referrals and service coordination, the type and number of programs that provide early identification and intervention services, and interagency coordination (Danaher et al., 2004).

Within individual programs, early intervention providers are recommended to implement broad-based developmental screening practices to identify children who may qualify for services, and families of children who are flagged as being at-risk are recommended to participate in a comprehensive evaluation to determine potential eligibility. Then, if children are identified as having a predetermined percentage delay in one or more developmental areas (including cognitive development, physical development, communication development, social or emotional development, and/or adaptive development), they are deemed eligible and permitted to receive early intervention services and supports from developmentally relevant providers (including physical therapists, occupational therapists, speech language pathologists, psychologists, and social workers). In addition to conducting broad-based developmental screening, some research has also attempted to introduce disorder-specific screening for ASD into early intervention programs. In a recent study by Rotholz et al. (2017), the South Carolina Act Early Team (SCAET) implemented a two-tiered gated screening process to increase early identification of young children at-risk for ASD and examine presumptive eligibility criteria for receipt of EIBI

services. Implemented collaboratively, this policy was proposed to allow children under the age of three years without a formal diagnosis of ASD to receive EIBI services on the basis of outcomes from a tiered screening model. Results of the study indicated that implementation of the presumptive eligibility ASD screening model in South Carolina was accompanied by significant increases in young children being eligible for and receiving EIBI services, as well as led to increases in the number of children referred for early comprehensive diagnostic evaluation and subsequently diagnosed with ASD. In addition to South Carolina, other early intervention programs in Illinois and Connecticut have also attempted to introduce disorder-specific screening for ASD into practice (Connecticut Birth to Three System, 2019; Roberts et al., 2019). Although early intervention providers have highlighted not feeling prepared to talk with families or perform disorder-specific screening for ASD, self-reports indicate that they are eager to receive training on how to identify early indicators of ASD and use standardized disorder-specific screening tools to promote earlier identification of young children with ASD (Pizur-Barnekow et al., 2012; Tomlin et al., 2013). To improve service delivery within the early intervention setting, clinical record review may assist in tracking this type of information and better understanding how access to early intervention services may translate into timely referral and diagnosis for ASD.

Factors Associated with the Pathway Toward Referral for and Diagnosis of ASD

To gain a more complete understanding of factors that contribute to the pathway towards a match between referral for ASD and subsequent diagnosis of ASD, a series of epidemiological studies have sought to examine the roles that various child-level, family-level, and referring

healthcare provider-level factors play in delaying, mitigating, or expediating early identification of children with ASD.

Paul (2018) completed a dissertation study in which data from the *2011 Survey of Pathways to Diagnosis and Services* (commonly referred to as *Pathways*) was utilized to examine factors associated with age of ASD diagnosis. This nationally representative survey, conducted by the National Center for Health Statistics (NCHS) State and Local Integrated Telephone Survey (SLAITS) Program, collected retrospective self-report data from caregivers of children diagnosed with ASD, ID, or DD via telephone interview and follow-up questionnaire. To be permitted to participate in the epidemiological survey, caregiver respondents must have had an eligible child between six and 17 years of age, lived in the same household as that child, and confirmed that the child was previously diagnosed with ASD, ID, or DD (Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, 2012). Through examination and analysis of electronically published *Pathways* data, the author was interested in exploring the influence that initial symptom presentation, self-reported caregiver concerns, referring healthcare provider response, and geographic location had on timeliness of identification and diagnosis of ASD. Regarding initial symptom presentation, results indicated that delayed onset of speech and language skills, complete lack of speech and language skills, loss of speech and language skills, and use of odd gestures were behaviors associated with earlier age of ASD diagnosis, ranging from 17 months earlier (loss of speech and language skills) to 2.5 years earlier (complete lack of speech and language skills). Regarding self-reported caregiver concerns, results suggested that caregiver-reported age of initial concern ranged from 2.0 to 2.5 years of age, as well as that earlier ages of

caregiver-reported behavioral concern were associated with earlier age of ASD diagnosis. Regarding referring healthcare provider response to caregiver concerns, results indicated that more active provider responses (participation in developmental screening, referral to ASD specialists) were associated with earlier age of ASD diagnosis. Furthermore, the study directly examined factors related to geographic location. Although early caregiver concerns, early consultation with healthcare providers, and active referral responses by referring healthcare providers were often associated with children living in rural communities, it took significantly longer for children living in the most rural counties to receive a diagnosis of ASD than those living in more urban areas. Thus, despite timely identification of early behaviors of concern, discussion with referring healthcare providers, and initiation of referrals, these findings suggest that children living in the most rural communities experienced later age of ASD diagnosis. While this research has important implications for understanding the impact of various factors associated with timeliness of ASD diagnosis, the author cited limitations regarding the type of data examined and utilized. In using data gathered through epidemiological survey, there was a potential for self-selection of who was willing to participate. By relying on retrospective caregiver self-report, there was an increased likelihood of recall bias contributing to inaccurate recollection of information and lack of access to confirmatory data (such as that available in medical claims data or electronic health records). Further, the study failed to gather geographic information from families at the time of diagnosis, which would allow for more accurate examination of how geography may have influenced timeliness of diagnosis. Therefore, to better understand the pathway towards referral for ASD and diagnosis of ASD, the author specifically

recommended that future research examine data from electronic health records to validate and confirm the demographic and medical information of patients.

In a series of dissertation studies, Brisendine (2018) sought to gain a deeper understanding of various social-ecological factors associated with obtaining an appropriate diagnosis of ASD through examination of epidemiological data from two different sources. In a first study, data from the *2011/2012 National Survey of Children's Health* (NSCH) was reviewed and analyzed. Conducted on behalf of the United States Department of Health and Human Services, the Health Resources Services Administration, and the Maternal and Child Health Bureau, this telephone survey collected information regarding the physical and emotional health of children from birth to 17 years of age via retrospective caregiver report. Through examination of data from the NSCH, the author was interested in understanding how race and ethnicity, sex, geographic location, and severity of comorbid disorders or disabilities were associated with receipt of diagnostic services for ASD. Results of the study found that children who were identified as Non-His/Lat B/AA were significantly less likely to receive a diagnosis of ASD compared to children who were identified as Non-His/Lat W/C, and children who were female were less likely to receive a diagnosis compared to those who were male. Regarding geographic location, results indicated that children residing outside of metropolitan areas were less likely to receive a diagnosis of ASD, aligning with data from Paul (2018) suggesting that children living in more rural locations experienced challenges with accessing timely diagnostic services. Furthermore, those with at least one moderate to severe disorder or disability other than ASD were more likely than those without another disorder or disability to receive a diagnosis, suggesting that connection to the healthcare system due to a comorbid diagnosis may be helpful

in eventually accessing a diagnosis of ASD. In a second study, data from the *Pathways* survey was assessed to understand how access to therapeutic support services within the community was associated with timeliness of ASD diagnosis, and results indicated that significantly lower levels of service use were associated with children who were diagnosed at later ages. Although this research provides valuable information for understanding factors associated with appropriate diagnosis, the author outlined limitations related to information gathered from the NSCH and *Pathways* datasets. Challenges related to potential recall bias of retrospective caregiver report were cited, as well as that analyses were additionally limited by completeness of available data and variables collected in the epidemiological studies. To continue gaining a more complete understanding of the pathway toward identification and diagnosis of ASD, the author highlighted that smaller-scale research studies (which examine available data at the community and/or state level) are needed to evaluate factors associated with delays to or facilitation of diagnosis.

In another study by Jo et al. (2015), the authors sought to explore age at ASD diagnosis across various racial and ethnic groups (Non-His/Lat W/C, Non-His/Lat B/AA, His/Lat Any Race [His/Lat AR]) by examining data from the *2009-2010 National Survey of Children with Special Health Care Needs* (NS-CSHCN). Conducted by the National Center for Health Statistics, this nationally representative survey involved randomly dialing and calling telephone numbers, selecting only households with children, and administering a screening instrument to families that self-identified as having children with special health care needs. To greater understand factors that may contribute to timeliness of diagnosis for ASD, the authors examined patterns regarding race and ethnicity, severity of ASD diagnosis, and co-occurring health conditions. Regarding race and ethnicity, results indicated that Non-His/Lat W/C children

between five to 17 years of age had the highest proportion of later diagnoses, while His/Lat AR children had the lowest. However, these findings varied by severity of ASD diagnosis. As such, Non-His/Lat W/C children who were identified as having mild to moderately severe ASD had significantly later diagnoses than Non-His/Lat B/AA and His/Lat AR children, but Non-His/Lat W/C children with ASD who were identified as having severe ASD had earlier diagnoses than Non-His/Lat B/AA and His/Lat AR children. Similar patterns were observed when comparing children with and without co-occurring diagnoses of ID. Given that prevalence estimates for ASD are relatively similar across racial and ethnic groups, the authors suggested that differences between age of diagnosis may have been driven by processes of under-representation and under-identification of older children with mild or moderate ASD who are Non-His/Lat B/AA or His/Lat AR. Further, results also indicated that Non-His/Lat W/C and Non-His/Lat B/AA children with a later age of ASD diagnosis were significantly more likely to have a co-occurring diagnosis of ADHD than those with an earlier diagnosis, which may contribute to an early "masking effect" of symptoms associated with other diagnoses. While these findings have important implications for better understanding factors associated with age of ASD diagnosis, the authors cited some limitations to the study. Among these included the inability to clinically validate outcome measures (including assigned diagnosis, indicated severity levels, co-occurring conditions, and specific age of diagnosis) collected through caregiver report, as well as the potential for some children to have been excluded given the need for caregivers to endorse both special healthcare needs and ASD to be permitted to participate in the epidemiological survey. Because of these limitations, the authors highlighted a need for future research to examine these issues.

Zeleke et al. (2019) conducted an investigation that examined steps in the pathway towards diagnosis and access to services between Non-His/Lat W/C families and racial/ethnic minority families (Non-His/Lat B/AA, His/Lat, and Other Race) of children with ASD. Again, examining data published from the *Pathways* survey, the authors sought to understand patterns in caregiver-reported developmental concerns, experiences with healthcare providers, and access to developmental screening between the two groups. Regarding developmental concerns, significant differences were found in the amount of concerns that caregivers had about their child's overall functioning, with Non-His/Lat W/C families reporting more concerns than racial/ethnic minority families. Specific analyses indicated that Non-His/Lat W/C families were more concerned about their child's cognitive development and overall language and communication development than racial/ethnic minority families. However, in terms of medical concerns, social concerns, and behavioral concerns, Non-His/Lat W/C families and racial/ethnic minority families reported similar levels of concern. Regarding experiences with referring healthcare providers, results indicated that racial/ethnic minority families were less likely than Non-His/Lat W/C families to contact healthcare professionals with concerns about their child's development. However, when examining data related to the child's age at which parents became concerned about development, no differences were found between Non-His/Lat W/C families and racial/ethnic minority families. Regarding access to developmental screening (either completed by the caregiver or referring healthcare provider), a significant relationship appeared between race/ethnicity and completion of developmental screening, such that Non-His/Lat W/C families more frequently completed screening measures with referring healthcare providers than minority families. Overall, racial/ethnic background of the family was commonly associated with

differences along the pathway towards diagnosis. However, because the authors of the study chose to aggregate all racial/ethnic minority groups into one category (racial/ethnic minority families), it is difficult to parse apart exactly where differences may have presented. Further, although retrospective caregiver report is often the mode of data collection in nationally representative studies, the potential for inaccurate recollection of developmental and diagnostic information exists. To address these limitations, the authors recommended that future research attempt to disaggregate data regarding race and ethnicity of families, as well as utilize different methodologies to examine factors associated with the pathway towards referral for and diagnosis of ASD. This could be accomplished by reviewing electronic clinical health records to disaggregate different variables of interest that may be predictive of ASD diagnosis.

In another study by Barnard et al. (2017), the authors were interested in further examining the relationship between referring healthcare provider responses, timeliness of diagnosis, and child age at receipt of ASD diagnosis. Through the use of nationally representative data from the *Pathways* survey, analyses were conducted to examine proactive (conducting developmental screening, referral to ASD specialists) and delayed (reassurance that nothing was wrong, mention that the child would appropriately progress) referring healthcare provider responses when caregivers disclosed concerns about ASD. Results of the study indicated that proactive referring healthcare provider responses were associated with younger ages of initial ASD diagnosis than delayed responses, with children belonging to the proactive provider response class being diagnosed over one year earlier than children belonging to the delayed provider response class. Further, the study also found that proactive healthcare responses were related to shorter time to receipt of diagnosis than delayed responses, with children

belonging to the proactive provider response class experiencing a 1.5 year less delay in accessing a diagnosis of ASD than those belonging to the delayed provider response class. These results suggested that a delayed referring healthcare provider response to caregiver-reported concerns was associated with older chronological age at time of ASD diagnosis, as well as greater delays between caregiver-report of initial concerns and eventual time of diagnosis. Although this study shed light on important information regarding referring healthcare provider behaviors and timeliness of ASD diagnosis, the authors cited limitations of not having objective clinical data to confirm assigned diagnoses or documented referring healthcare provider responses, and offered the recommendation for future research to examine formally documented information. The authors also outlined the need for future inclusion and comparison of data for children who are not referred and/or diagnosed with ASD. This type of information could be identified by examining the clinical health records of children referred for specialized ASD assessments, as well as analyzing the clinical data of children who were and were not ultimately diagnosed with ASD.

In another nationally representative study, Zuckerman et al. (2015) were interested in examining the age of initial caregiver-reported concern, initial caregiver discussion of concerns with referring healthcare providers, and type of healthcare provider response for children diagnosed with ASD compared to children diagnosed with ID or DD. Further, among children with ASD, the authors also sought to explore whether a more proactive referring healthcare provider response to caregiver-reported concerns was associated with earlier ASD diagnosis when compared to a delayed referring healthcare provider response. Published data from the *Pathways* study was again utilized. Regarding comparisons between children with ASD, ID and

DD, the study found that children with ASD had an earlier age of initial caregiver-reported concern (2.1 years of age) compared to children with ID/DD (3.0 years of age), as well as earlier caregiver discussion of concerns with a referring healthcare provider (2.3 years of age) compared to those with ID/DD (3.2 years of age). Children with ASD and comorbid ID/DD had an earlier age of initial caregiver-reported concern (1.9 years of age) when compared to children with ASD only (2.5 years of age) or ID/DD only (3.0 years of age). Further, caregiver discussion of concerns with a referring healthcare provider occurred significantly earlier for children with ASD and comorbid ID/DD (2.0 years of age) compared to children with ID/DD only (3.2 years of age). Results suggested that children with ASD and comorbid ID/DD were diagnosed earlier (4.8 years of age) than children with ASD only (6.0 years of age), and mean delay between initial caregiver discussion with a referring healthcare provider and delivery of the ASD diagnosis was 2.7 years. Regarding the relationship between diagnostic delay and referring healthcare provider response, children with ASD were shown to have significantly fewer proactive responses (conduction of developmental screening, referral to ASD specialists, discussion of concerns with the school) and more delayed responses (reassurance that nothing was wrong, mention that the child would appropriately progress) by referring healthcare providers when caregivers reported concerns compared to children with ID/DD. However, similar to findings from Barnard et al. (2017), results indicated that each proactive response to caregiver-reported concerns was associated with a reduction of at least one year in delay from initial discussion of concerns to receipt of ASD diagnosis, producing significant decreases in diagnostic delay. While these findings suggested that referring healthcare provider responses to initial caregiver concerns may contribute to facilitation or delay of diagnosis, several limitations were noted. Due to the self-

report nature of the survey data, the authors highlighted that some outcomes may reflect emotional reactions of caregivers regarding overall quality of healthcare services rather than specific actions that referring healthcare providers took. Further, because all information was based on retrospective report, there was no way for the authors to assess the validity of indicated diagnoses or various points in time along the pathway. Thus, the authors recommended that future research attempt to explore and address these limitations. To gather this information and address limitations of the study, future studies could examine clinic observation or progress notes, diagnostic assessment results, and structured interview outcomes from clinical visits. Electronic health records are a comprehensive and available source of this type of information and should be significantly considered for data gathering and analysis.

Conclusion

Although psychometrically sound screening and diagnostic assessment measures exist and a reliable diagnosis of ASD can be made before children are the age of two (Centers for Disease Control and Prevention, 2014; Guthrie et al., 2013; Kleinman et al., 2008), current reports suggest that the average age of initial diagnosis in the United States is four years and four months (Centers for Disease Control and Prevention, 2020). Further, almost 30% of children who meet criteria for ASD have not received an official diagnosis by the age of eight (Baio et al., 2018; Centers for Disease Control and Prevention, 2020). Limited availability of practitioners who can diagnose, long wait lists for diagnostic appointments, limited age ranges covered by disorder-specific screening tools, and challenges with consistent implementation of broad-based developmental screening and disorder-specific screening for ASD have all been identified as contributing factors to delays in age of ASD diagnosis (Arunyart et al., 2012; Coury et al., 2017;

Matson & Goldin, 2014). Delayed identification and diagnosis can significantly reduce access to essential EIBI treatment services and hinder the promotion of positive developmental trajectories for all individuals with ASD. It is essential that research fully examine the pathway towards referral and diagnosis of ASD, both to understand the causes of delayed diagnosis and to promote earlier identification and referral.

While some epidemiological studies have begun to analyze factors associated with facilitation of or delays to ASD diagnosis (Barnard et al., 2017; Brisendine, 2018; Jo et al., 2015; Paul, 2018; Zeleke et al., 2019; Zuckerman et al., 2015), this research has primarily focused on examination of information gathered through retrospective caregiver report and analysis of data available at the population-level. Although conclusions drawn from data gathered in this manner are extremely valuable and provide insight into various factors that contribute to the pathway towards identification, it is impossible to confirm the clinical validity of this information. Further, despite recommendations for future research to confirm clinical information through examination of data recorded in medical claims reports or electronic health records, no known studies to date have examined factors associated with the pathway toward referral and diagnosis in this manner. Thus, this type of research is desperately needed before strong conclusions can be drawn regarding which child-related, family-related, and referring healthcare provider-related factors contribute to a timely referral for and diagnosis of ASD.

Purpose of Research

Based on information outlined in the current literature, there continue to be gaps in what is known about the pathway towards referral for and subsequent diagnosis of ASD, as well as opportunities to apply novel methodology to improve understanding of factors contributing to

early identification of children with the disorder. Therefore, the current study sought to extend what is known and utilize a multi-method approach to address limitations in the literature. Given the importance of early identification, diagnosis, and intervention for children with ASD (Hyman et al., 2020), this exploratory research study involved examination of clinical data from the electronic health records of infants, children, and adolescents seen in a specialty autism diagnostic clinic. The goals of this study were to better understand the array of child-related, family-related, and referring healthcare provider-related factors that contribute to matched referral for and subsequent diagnosis of ASD, as well as to identify factors specifically associated with early identification and referral of children at or under the age of three. By gaining an increased understanding of the multitude of factors that influence access to timely referral and diagnostic services, it will become possible to further clarify the driving forces that delay, mitigate, or expediate the pathway and identify how to best promote optimal outcomes for children with ASD.

Research Questions of the Current Study

Given the identified gaps in the literature, the current study sought to address two primary research questions. The two primary research questions and a series of associated sub-questions are as follows:

Primary Research Question #1:

1. For children who were seen by a professional in a specialty autism diagnostic clinic, what child-related, family-related, and/or referring healthcare provider-related factors were associated with matched referral for ASD and subsequent diagnosis of ASD?

a. Sub-Question 1.1: For children who were seen by a professional in a specialty autism diagnostic clinic, what child-related factors were associated with matched referral for ASD and subsequent diagnosis of ASD?
b. Sub-Question 1.2: For children who were seen by a professional in a specialty autism diagnostic clinic, what family-related factors were associated with matched referral for ASD and subsequent diagnosis of ASD?
c. Sub-Question 1.3: For children who were seen by a professional in a specialty autism diagnostic clinic, what referring healthcare provider-related factors were associated with matched referral for ASD and subsequent diagnosis of ASD?

Primary Research Question #2:

2. What detectable differences in child-related, family-related, and referring healthcare provider-related factors exist between children who were referred to a specialty autism diagnostic clinic before/at three years of age versus after three years of age?
    a. Sub-Question 2.1: What detectable differences in child-related factors exist between children who were referred to a specialty autism diagnostic clinic before/at three years of age versus after three years of age?
    b. Sub-Question 2.2: What detectable differences in family-related factors exist between children who were referred to a specialty autism diagnostic clinic before/at three years of age versus after three years of age?
    c. Sub-Question 2.3: What detectable differences in referring healthcare provider-related factors exist between children who were referred to a specialty autism diagnostic clinic before/at three years of age versus after three years of age?

Chapter 2

Methods

The purpose of this chapter is to present the methods for the current research study. First, this chapter provides information about the setting and participants, as well as inclusion and exclusion criteria for the study. Next, information regarding dependent measures, research design, and procedures is presented, and a detailed description of all measures that were extracted from electronic health records is reviewed. Finally, this information is followed by discussion of statistical analyses completed to address each research question.

Setting

Data for this study was collected using a retrospective electronic health record review of all patients seen for an initial diagnostic evaluation within a year-long period from a specialty diagnostic clinic at the University of Wisconsin – Madison. The Autism and Developmental Disabilities (A&DD) Clinic, associated with the University of Wisconsin – Madison Waisman Center, is an interdisciplinary diagnostic clinic for children and adolescents with concerns regarding a range of developmental delays and disabilities located in Madison, Wisconsin. Services provided by the A&DD Clinic include diagnostic evaluation appointments with individual clinicians or teams of clinicians from various professional disciplines, such as psychology, developmental pediatrics, speech-language pathology, audiology, occupational therapy, nutrition, nursing, and social work.

At the beginning of the evaluation process, patients are referred to the A&DD Clinic for concerns related to ASD, ID, and/or developmental delays (DD). Diagnostic referrals come from primary and specialty healthcare providers across the state of Wisconsin and various neighboring

states (including Illinois, Iowa, and Minnesota). Upon receipt of referral, clinical directors and staff review the referring healthcare provider's referral question and determine its relevance to the scope of clinical services offered through the A&DD Clinic. If a referral is determined to be outside the scope of offered services (not aligning with concerns related to ASD, ID, or DD), families are referred to other diagnostic and/or treatment providers within the community who are better suited to address the indicated concerns. However, for patients whose referral concern falls within the scope of the clinic's practice, families are asked to participate in an initial phone screening interview to gather additional information about the referral and determine which members of the interdisciplinary team are needed to participate in the diagnostic evaluation process. Upon completion of the phone screening, patients are then added to an evaluation waitlist and families are contacted for scheduling once a diagnostic appointment slot becomes available with a clinical provider. Throughout receipt of diagnostic services in the A&DD Clinic, patients and families engage in comprehensive intake interviews to clarify developmental history and current concerns, participate in evidence-based assessment activities based on indicated referral concerns (including cognitive, behavioral, speech-language, motor, social-emotional, and/or adaptive behavior assessment measures), and receive interdisciplinary treatment recommendations and resources at the conclusion of the diagnostic process. Depending on whether diagnostic criteria are met, many children and adolescents also receive official medical diagnoses following services in the A&DD Clinic. Aspects of these clinical activities which are relevant to identification of information for the current study will be further described below.

Participants

The HealthLink electronic health records of all pediatric patients seen by clinicians for an initial diagnostic evaluation in the A&DD Clinic between September 12, 2019 and September 12, 2020 were reviewed. Electronic health records were examined and included information prior to and through receipt of the A&DD diagnostic clinic appointments only. This particular time period was selected because clinic visit schedules only remain active in the HealthLink electronic health record for up to one year. Thus, it was only possible to electronically access one year of active data linked to A&DD clinic visits. The total sample size from the one-year period was 371 separate pediatric electronic health records. A full age range of records was reviewed (including infants, children, and adolescents between the ages of zero and 18) for individuals who were referred to and assessed in the A&DD Clinic. After review, HealthLink electronic health records were broken into two separate groups – electronic health records of individuals at or younger than three years of age (up to 47 months of age), and electronic health records of individuals older than three years of age (at or older than 48 months of age). Selection of records for review began with patients who were seen by a provider in the clinic for an initial diagnostic appointment recorded on September 12, 2019 and progressed forward (through September 12, 2020) until all electronic health records within the outlined sample groups were reviewed. Records for both male and female individuals were included. It is important to note that approximately half of the reviewed records were abstracted during the COVID-19 pandemic (beginning March 16, 2020, and continuing through September 12, 2020), which may have impacted how families received community-based services prior to referral, were referred to the specialty diagnostic clinic, and participated in the diagnostic evaluation process. Because the

purpose of the study was to better understand various factors that contributed to both a referral for ASD and subsequent diagnosis of ASD, the records of individuals referred for both ASD and other concerns (ID, DD), as well as those diagnosed with both ASD and other disorders (ID, global developmental delay, genetic differences/disorders, speech-language impairment, ADHD, etc.), were included. Given the nature of the study and data collection procedures, a waiver of informed consent was requested and obtained through the University of Wisconsin – Madison Institutional Review Board (IRB). Since clinical data were already available for review and all patient information was aggregated for the current study, there was little to no risk that information regarding patient identity would be revealed.

Research Design and Procedures

Given that clinical data were already collected during diagnostic appointments with clinicians in the A&DD Clinic and recorded in HealthLink electronic health records, this study utilized a descriptive observational design to retrospectively review, extract, code, and analyze available data from patient records. Prior to data collection, Clinic – Research Collaboration (CRC) approval was sought and obtained from the Clinical Translational Core (CTC) at the University of Wisconsin – Madison Waisman Center. This CRC approval process, which is required for all research projects involving data collection from the Waisman Center Clinics, was designed to ensure that research activities are congruent with the mission of the Waisman Center and current policies in the Waisman Center Clinics. During this process, the primary researcher was also required to complete mandatory health clearance training and obtain cleared approval from the CTC. After receiving CRC and CTC approval, IRB approval was then sought and obtained from the Minimal Risk Health Sciences IRB at the University of Wisconsin – Madison.

Then, following approval from the CRC, CTC, and Minimal Risk Health Sciences IRB, retrospective review of electronic health records and extraction of clinical data was initiated.

HealthLink electronic health record data was accessed through password-protected computers located in the locked teaming room area of the A&DD Clinic. Data for all factors of interest was directly extracted and recorded onto electronic data collection sheets, which were saved in a file of completed electronic data collection sheets. This was done to ensure that all raw data were saved electronically and available for reliability coding purposes. Collected information was then reviewed, classified, coded, and saved in an Excel database file. The electronic data collection sheets and Excel database file were stored in a confidential manner within an electronic Protected Health Information (ePHI) HIPAA-secure Restricted ResearchDrive folder, using a password-protected laptop computer configured in accordance with guidance from the Office of Cybersecurity at the University of Wisconsin – Madison. The ePHI Restricted ResearchDrive folder was accessed on the configured password-protected laptop for the duration of all data collection and analysis activities. Each participant was given a subject identification number, which maintained confidentiality for data storage and statistical analyses. Subject identification numbers and electronic health records were linked through use of Medical Record Numbers (MRNs) saved on a separate Excel database file in the ePHI Restricted ResearchDrive folder. No names or identifiable information from participants were used throughout the study.

Measures

Summary of Factors for Extraction and Coding

Detailed descriptions and numerical codes for all child-related, family-related, and referring healthcare provider-related factors (independent variables) that were reviewed, extracted, and recorded from electronic health records, as well as dependent variables (referral for ASD and subsequent diagnosis of ASD; timeliness of referral to the diagnostic clinic), are provided below. Additional information is also included regarding where in the electronic health record the primary researcher explicitly searched for and identified different factors. See **Appendix 1** for a copy of the descriptive data collection sheet that was used during review of electronic records and extraction of clinical data.

Child-Related Factors

Current Assignment of ASD Diagnosis. In order to determine the outcome of the A&DD Clinic visit regarding whether or not the child was diagnosed with ASD, electronic health records were reviewed to identify if an infant, child, or adolescent received a DSM-5 diagnosis of ASD following receipt of diagnostic services. Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Key phrases may have included notation of a current "autism" or "autism spectrum disorder" diagnosis. Current assignment of ASD diagnosis was coded as follows: 0 = no current diagnosis of ASD; 1 = current diagnosis of ASD. This was a binary type variable, and was selected given its inclusion in previous research investigations (as indicated in the literature review).

Previous Assignment of ASD Diagnosis. It was possible that infants, children, or adolescents may have received a previous diagnosis of ASD prior to referral to the A&DD Clinic. Therefore, electronic health records were searched to determine whether a previous DSM diagnosis of ASD was assigned. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This information was specifically located in the "previously assigned diagnosis" section of these documents, and key phrases may have included notation of a previous "autism" or "autism spectrum disorder" diagnosis. Previous assignment of ASD diagnosis was coded as follows: 0 = no previous diagnosis of ASD/unknown previous diagnosis of ASD; 1 = previous diagnosis of ASD. This was a binary type variable and chosen based on its inclusion in prior research studies (as previously outlined in the literature review).

Ever Assignment of ASD Diagnosis. To determine whether an infant, child, or adolescent ever received a diagnosis of ASD, electronic health records were reviewed to determine if a current or previous ASD diagnosis was assigned. This variable was created by combining information from the two prior variables ("Current Assignment of ASD Diagnosis" and "Previous Assignment of ASD Diagnosis") to assist with running planned statistical analyses. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This information was specifically located in the "currently assigned diagnosis" or "previously assigned diagnosis" sections of these documents, and key phrases may have included

notation of a current or previous “autism” or “autism spectrum disorder” diagnosis. Ever assignment of ASD diagnosis was coded as follows: 0 = never diagnosis of ASD/unknown ever diagnosis of ASD; 1 = ever diagnosis of ASD. This was a binary type variable, and was included given its use in previous studies (as indicated in the literature review).

Assignment of Level of Support for ASD Diagnosis. If a DSM-5 diagnosis of ASD was identified (either from the A&DD Clinic visit or as part of a previous diagnosis), individuals were also assigned a severity level score. These scores include Level 1 (“Requiring support”), Level 2 (“Requiring substantial support”), and Level 3 (“Requiring very substantial support”). If data was extracted regarding current or previous assignment of ASD diagnosis, electronic health records were also examined to determine the indicated level of support associated with the ASD diagnosis. This factor served as a proxy for level of severity associated with the diagnosis. Information related to this factor was searched for and identified in the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. If available, this data was specifically located in the “currently assigned diagnosis” or “previously assigned diagnosis” sections of these documents, and specific key words may have included “level of support” or “level of severity.” Assignment of level of support for ASD diagnosis was coded as follows: NA = not applicable (for those who did not receive a diagnosis of ASD); 1 = level 1 (requiring support); 2 = level 2 (requiring substantial support); 3 = level 3 (requiring very substantial support); 4 = not reported in record (for those who received a diagnosis of ASD but did not have information regarding level of support included in the electronic health record).

This was a categorical type variable, and was selected given its inclusion in previous empirical investigations (as noted previously in the literature review).

Current Assignment of ID Diagnosis. In order to determine additional outcome of the A&DD Clinic visit, beyond whether or not the child was diagnosed with ASD, electronic health records were also reviewed to identify if a child or adolescent received a DSM-5 diagnosis of ID following receipt of services from the A&DD Clinic. Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Key words may have included notation of current "intellectual disability" diagnoses. Current assignment of ID diagnosis was coded as follows: 0 = no current diagnosis of ID; 1 = current diagnosis of ID. This was a binary type variable and included given its use in prior studies (as outlined in the literature review).

Previous Assignment of ID Diagnosis. In order to determine if children or adolescents received a previous DSM diagnosis of ID prior to the A&DD Clinic visit, electronic health records were searched to identify if a prior diagnosis of ID was indicated. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. This information was specifically located in the "previously assigned diagnosis" section of these documents, and key words may have included notation of previous "intellectual disability" diagnoses. Previous assignment of ID diagnosis was coded as follows: 0 = no previous diagnosis of ID; 1 = previous diagnosis of ID. This was a binary type

variable, and was selected based on its inclusion in previous investigations (as previously mentioned in the literature review).

Ever Assignment of ID Diagnosis. To determine whether a child or adolescent ever received a diagnosis of ID, electronic health records were reviewed to determine if a current or previous ID diagnosis was assigned. This variable was created by combining information from the two prior variables ("Current Assignment of ID Diagnosis" and "Previous Assignment of ID Diagnosis") to assist with running planned statistical analyses. Data related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specifically, this information was either located in the "currently assigned diagnosis" or "previously assigned diagnosis" sections of these documents, and key words may have included current or previous "intellectual disability" diagnoses. Ever assignment of ID diagnosis was coded as follows: 0 = never diagnosis of ID; 1 = ever diagnosis of ID. This was a binary type variable and chosen given its evaluation in prior research studies (as highlighted in the literature review).

Assignment of Severity for ID Diagnosis. For similar reasons as described for ASD severity levels, following extraction of data regarding current or previous assignment of ID diagnosis, electronic health records were also examined to determine the indicated level of severity associated with the ID diagnosis. Information related to this factor was searched for and identified in the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic.

If available, this data was specifically located in the "currently assigned diagnosis," "previously assigned diagnosis," or "cognitive assessment results" sections of these documents. Key words, such as IQ scores indicating "mild," "moderate," "severe," or "profound" functional impairments, were used to identify severity. Assignment of severity for ID diagnosis was coded as follows: NA = not applicable (for those who did not receive a diagnosis of ID); 1 = mild severity; 2 = moderate severity; 3 = severe severity; 4 = profound severity; 5 = not reported in record (for those who received a diagnosis of ID but did not have information regarding level of severity included in the electronic health record). This was a categorical type variable and included given its presence in previous investigations (as noted in the literature review).

Full Scale Cognitive Assessment Score Achieved. When a cognitive assessment was conducted with the child or adolescent as part of the diagnostic evaluation for ID in the A&DD Clinic visit, electronic health record information was examined to determine the full scale cognitive assessment score that the child or adolescent achieved following an assessment appointment. Scores may have been included from the *Wechsler Intelligence Scale for Children, Fifth Edition* (WISC-V; Wechsler, 2014), the *Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition* (WPPSI-IV; Wechsler, 2012), the *Stanford-Binet Intelligence Scales, Fifth Edition* (SB-5; Roid & Pomplun, 2014), the *Leiter International Performance Scale, Third Edition* (Leiter-3; Roid et al., 2013), or the *Differential Ability Scales-II* (DAS-II; Elliott, 2007). Full scale assessment scores were fully written out and recorded as such. A code of "NA" indicated that this information was either not relevant (if the infant, child, or adolescent did not participate in a cognitive assessment as part of the diagnostic evaluation process) or not reported in the electronic health record. Information related to this factor was searched for and

identified in the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. If available, this data was specifically located in the "cognitive assessment results" section of these documents and included numeric scores. This was a continuous type variable, and was included as an exploratory factor given its relationship to presence and severity of ID diagnosis.

Current Assignment of Global Developmental Delay Diagnosis. To determine additional outcome of the A&DD Clinic visit, beyond whether or not the child was diagnosed with ASD or ID, electronic health records were also reviewed to identify if an infant or child received a DSM-5 diagnosis of global developmental delay following receipt of services from the A&DD Clinic. Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Key words may have included notation of current "global developmental delay" or "developmental delay" diagnoses. Current assignment of global developmental delay diagnosis was coded as follows: 0 = no current diagnosis of global developmental delay; 1 = current diagnosis of global developmental delay. This was a binary type variable and selected based on its inclusion in previous empirical investigations (as mentioned in the literature review).

Previous Assignment of Global Developmental Delay Diagnosis. To determine if infants or children received a previous DSM diagnosis of global developmental delay prior to the A&DD Clinic visit, electronic health records were searched to identify whether a prior diagnosis of global developmental delay was indicated. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or

diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. This data was specifically identified in the "previously assigned diagnosis" section of these documents, and key words may have included notation of previous "global developmental delay" or "developmental delay" diagnoses. Previous assignment of global developmental delay diagnosis was coded as follows: 0 = no previous diagnosis of global developmental delay; 1 = previous diagnosis of global developmental delay. This was a binary type variable, and was chosen given its analysis in prior studies (as previously indicated in the literature review).

Full Scale Developmental Quotient Score Achieved. When a developmental assessment was conducted with the infant or child as part of the diagnostic evaluation for global developmental delay in the A&DD Clinic visit, electronic health record information was reviewed to determine the full scale developmental quotient score that the infant or child achieved following an assessment appointment. Scores may have been included from the *Bayley Scales of Infant and Toddler Development, Third Edition* (Bayley-III; Bayley, 2006), *Bayley Scales of Infant and Toddler Development, Fourth Edition* (Bayley-IV; Bayley & Aylward, 2019), or the *Mullen Scales of Early Learning* (Mullen; Mullen, 1995). Full scale developmental quotient scores were fully written out and recorded as such. A code of "NA" indicated that this information was either not relevant (if the infant, child, or adolescent did not participate in a developmental assessment as part of the diagnostic evaluation process) or not reported in the electronic health record. Information related to this factor was searched for and identified in the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. If available, this data was specifically located in the

"developmental assessment results" section of the documents and included numeric scores. This was a continuous type variable, and was included as a novel factor given its relationship to presence or absence of GDD diagnosis.

Current Assignment of Speech-Language Diagnosis. To determine additional outcome of the A&DD Clinic visit, beyond whether a child was diagnosed with ASD, ID, or global developmental delay, electronic health records were also examined to identify if an infant, child, or adolescent received a DSM-5 diagnosis of a speech-language communication disorder following receipt of services from the A&DD Clinic. These diagnoses may have included a language disorder/delay (expressive, receptive, or mixed), social pragmatic communication disorder, speech sound disorder, or childhood-onset fluency disorder (stuttering). Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of speech-language pathology, psychology, or developmental pediatric clinicians from the A&DD Clinic. Key words may have included notation of current "mixed expressive-receptive delay," "expressive language disorder," or "speech sound disorder" diagnoses. Current assignment of speech-language disorder diagnosis was coded as follows: 0 = no current diagnosis of speech-language disorder; 1 = current diagnosis of speech-language disorder. This was a binary type variable and selected given its use in prior research studies (as noted in the literature review).

Previous Assignment of Speech-Language Diagnosis. To determine if infants, children, or adolescents received a previous DSM diagnosis of a speech-language disorder prior to the A&DD Clinic visit, electronic health records were searched to identify whether a previous DSM diagnosis of a speech-language disorder was indicated. Information related to this factor was

searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of speech-language pathology, psychology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified in the "previously assigned diagnosis" section of these documents, and key words may have included notation of previous "mixed expressive-receptive language delay," "receptive language disorder," or "expressive language disorder" diagnoses. Previous assignment of speech-language disorder diagnosis was coded as follows: 0 = no previous diagnosis of speech-language disorder; 1 = previous diagnosis of speech-language disorder. This was a binary type variable, and was chosen given its evaluation in prior research (as previously highlighted in the literature review).

Current Assignment of Genetic Disorder/Difference Diagnosis. To determine additional outcome of the A&DD Clinic visit, beyond whether or not the child was diagnosed with any of the previous disorders, electronic health records were also reviewed to identify if an infant, child, or adolescent received a diagnosis of a genetic disorder or difference following receipt of services from the A&DD Clinic. Some indicated diagnoses may have included an array of different chromosomal deletions or duplications (such as 16q23.3 deletion, 16q24.1 deletion, 9p21.1 deletion, 1p13.3 duplication, and 3p25.2 duplication). Information related to this factor was searched for and identified in the "currently assigned diagnosis section" of visit progress notes and/or diagnostic evaluation reports of developmental pediatric clinicians from the A&DD Clinic or medical genetic clinicians who consulted with providers in the A&DD Clinic. Key phrases may have included notation of a current chromosomal deletion, such as "16q23.3 deletion," or chromosomal duplication, such as "3p25.2 duplication." Current assignment of genetic disorder/difference diagnosis was coded as follows: 0 = no current genetic

disorder/difference diagnosis; 1 = current genetic disorder/difference diagnosis. This was a binary type variable, and chosen based on its inclusion in previous investigations (as indicated in the literature review).

Previous Assignment of Genetic Disorder/Difference Diagnosis. To determine if infants, children, or adolescents received a previous diagnosis of a genetic disorder prior to the A&DD Clinic visit, electronic health records were searched to identify whether a prior diagnosis of a genetic disorder or difference was indicated. Some previous diagnoses may have included Down Syndrome, Doose Syndrome (myoclonic-astatic epilepsy), Cystic Fibrosis, von Willebrand Disease, Mosaic XYY, DiGeorge Syndrome, Cerebral Palsy, Neurofibromatosis, Duane Syndrome, Wiedeman-Steiner Syndrome, Scaff-Yang Syndrome, Eagle-Barrett Syndrome, Hypermobiel Ehler-Danlos Syndrome, Leri-Weill Dyschondrosteosis, Septo-Optic Dysplasia, Tuberous Sclerosis, Neuronal Ceroid-Lipofuscinosis (Type 2), Bohring-Optiz Syndrome, Polymicrogyria, Multiple Endocrine Neoplasia (Type 1), Noonan Syndrome, Stickler Syndrome, and an array of different chromosomal deletions or duplications (such as CADP52 deletion, TUBB2A mutation, 22q11.2 deletion, 4q28.1 deletion, 16q21 deletion, 7q36.1 deletion, 10q11.22-23 deletion, 15q13.3 deletion, 16p11.2 deletion, and 16p11.2 duplication). Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of developmental pediatric clinicians from the A&DD Clinic or medical genetic clinicians who consulted with providers in the A&DD Clinic. Specifically, this data was identified in the “previously assigned diagnosis” section of these documents, and key words may have included notation of previous “Trisomy 21/Down Syndrome,” “Septo-Optic Dysplasia,” or “Noonan Syndrome” diagnoses. Previous

assignment of genetic disorder/difference diagnosis was coded as follows: 0 = no previous genetic disorder/difference diagnosis; 1 = previous genetic disorder/difference diagnosis. This was a binary type variable and included given its use in prior investigations (as indicated previously in the literature review).

Ever Assignment of Genetic Disorder/Difference Diagnosis. To determine whether an infant, child, or adolescent ever received a diagnosis of a genetic disorder/difference, electronic health records were reviewed to determine if a current or previous genetic disorder/difference diagnosis was assigned. This variable was created by combining information from the two prior variables ("Current Assignment of Genetic Disorder/Difference Diagnosis" and "Previous Assignment of Genetic Disorder/Difference Diagnosis") to assist with running planned statistical analyses. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic or medical genetic clinicians who consulted with providers in the A&DD Clinic. More specifically, this data was identified in the "currently assigned diagnosis" or "previously assigned diagnosis" sections of these documents, and key words may have included notation of "Trisomy 21/Down Syndrome," "Noonan Syndrome," "16q23.3 deletion," or "3p25.2 duplication" diagnoses. Ever assignment of genetic disorder/difference diagnosis was coded as follows: 0 = never diagnosis of genetic disorder/difference; 1 = ever diagnosis of genetic disorder/difference. This was a binary type variable, and was selected based on its analysis in previous research studies (as outlined in the literature review).

Current Assignment of Other Diagnosis. To determine additional outcome of the A&DD Clinic visit, electronic health records were also reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of another disorder (besides those previously outlined) following receipt of services from the A&DD Clinic. Indicated diagnoses may have included ADHD, a type of anxiety, obsessive compulsive, or adjustment disorder, or a type of mood disorder. Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Key words may have included specific notation of current "ADHD – combined presentation," "generalized anxiety disorder," or "disruptive mood dysregulation disorder" diagnoses. Current assignment of other diagnosis was coded as follows: 0 = no current diagnosis of another disorder; 1 = current diagnosis of another disorder. This was a binary type variable, and included given its use in reviewed research investigations (as described in the literature review).

Previous Assignment of Other Diagnosis. To determine if children or adolescents received a previous DSM diagnosis of another disorder prior to the A&DD Clinic visit, electronic health records were searched to identify whether another DSM diagnosis (besides those previously outlined) was indicated. Previous diagnoses may have included ADHD, a type of anxiety, obsessive compulsive, or adjustment disorder, or a type of mood disorder. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified in the "previously assigned diagnosis" section of these documents, and key words may have

included “ADHD – primarily inattentive presentation,” “social anxiety disorder,” or “disruptive mood dysregulation disorder” diagnoses. Previous assignment of other diagnosis was coded as follows: 0 = no previous diagnosis of another disorder; 1 = previous diagnosis of another disorder. This was a binary type variable, and was chosen based on its inclusion in previous studies (as indicated in the literature review).

Current Assignment of Other Diagnosis – ADHD. To determine additional outcome of the A&DD Clinic visit, electronic health records were also reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of ADHD following receipt of services from the A&DD Clinic. ADHD diagnoses may have included combined presentation ADHD, predominantly inattentive presentation ADHD, predominantly hyperactive/impulsive presentation ADHD, other specified ADHD, or unspecified ADHD. Information related to this factor was searched for and identified in the “currently assigned diagnosis” section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Key words may have included notation of current “ADHD – primarily inattentive presentation” or “ADHD – combined presentation” diagnoses. Current assignment of ADHD diagnosis was coded as follows: 0 = no current diagnosis of ADHD; 1 = current diagnosis of ADHD. This was a binary type variable and selected based on its evaluation in previous investigations (as outlined in the literature review).

Previous Assignment of Other Diagnosis – ADHD. To determine if children or adolescents received a previous DSM diagnosis of ADHD prior to the A&DD Clinic visit, electronic health records were searched to identify whether a prior diagnosis of ADHD was indicated. Previously assigned ADHD diagnoses may have included combined presentation

ADHD, predominantly inattentive presentation ADHD, predominantly hyperactive/impulsive presentation ADHD, other specified ADHD, or unspecified ADHD. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified in the "previously assigned diagnosis" section of these documents, and key words may have included notation of previous "ADHD – combined presentation" or "ADHD – primarily hyperactive/impulsive presentation" diagnoses. Previous assignment of ADHD diagnosis was coded as follows: 0 = no previous diagnosis of ADHD; 1 = previous diagnosis of ADHD. This was a binary type variable, and was included given its use in previous studies (as described in the literature review).

Current Assignment of Other Diagnosis – Anxiety/Obsessive Compulsive/ Adjustment Disorder. To determine additional outcome of the A&DD Clinic visit, electronic health records were reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of an anxiety, obsessive compulsive, or adjustment disorder following receipt of services from the A&DD Clinic. Anxiety disorder diagnoses may have included separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, generalized anxiety disorder, other specified anxiety disorder, or unspecified anxiety disorder. Obsessive compulsive disorder diagnoses may have included obsessive compulsive disorder, other specified obsessive compulsive and related disorder, or unspecified obsessive compulsive and related disorder. Adjustment disorder diagnoses may have included adjustment disorder. Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric

clinicians from the A&DD Clinic. Specific key words may have included notation of current "generalized anxiety disorder" or adjustment disorder" diagnoses. Current assignment of anxiety/obsessive compulsive/adjustment disorder diagnosis was coded as follows: 0 = no current diagnosis of anxiety/obsessive compulsive/adjustment disorder; 1 = current diagnosis of anxiety/obsessive compulsive/adjustment disorder. This was a binary type variable and selected given its inclusion in prior research investigations (as outlined in the literature review).

Previous Assignment of Other Diagnosis – Anxiety/Obsessive Compulsive/ Adjustment Disorder. To determine if children or adolescents received a previous DSM diagnosis of an anxiety, obsessive compulsive, or adjustment disorder prior to the A&DD Clinic visit, electronic health records were searched to identify whether a prior diagnosis of an anxiety, obsessive compulsive, or adjustment disorder was indicated. Anxiety disorder diagnoses may have included separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, generalized anxiety disorder, other specified anxiety disorder, or unspecified anxiety disorder. Obsessive compulsive disorder diagnoses may have included obsessive compulsive disorder, other specified obsessive compulsive and related disorder, or unspecified obsessive compulsive and related disorder. Adjustment disorder diagnoses may have included adjustment disorder. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified in the "previously assigned diagnosis" section of these documents, and key words may have included notation of previous "social anxiety disorder" or "obsessive compulsive disorder" diagnoses. Previous assignment of an anxiety/obsessive compulsive/adjustment

disorder diagnosis was coded as follows: 0 = no previous diagnosis of anxiety/obsessive compulsive/adjustment disorder; 1 = previous diagnosis of anxiety/obsessive compulsive/adjustment disorder. This was a binary type variable, and was selected based on its analysis in previous studies (as previously highlighted in the literature review).

Current Assignment of Other Diagnosis – Mood Disorder. To determine additional outcome of the A&DD Clinic visit, electronic health records were reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of a mood disorder following receipt of services from the A&DD Clinic. Mood disorder diagnoses may have included bipolar disorders, disruptive mood dysregulation disorder, major depressive disorder, other specified depressive disorder, or unspecified depressive disorder. Information related to this factor was searched for and identified in the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specific key words may have included notation of current "other specified depressive disorder" or "disruptive mood dysregulation disorder" diagnoses. Current assignment of mood disorder diagnosis was coded as follows: 0 = no current diagnosis of mood disorder; 1 = current diagnosis of mood disorder. This was a binary type variable, and was chosen given its inclusion in previous research (as described in the literature review).

Previous Assignment of Other Diagnosis – Mood Disorder. To determine if children or adolescents received a previous DSM diagnosis of a mood disorder prior to the A&DD Clinic visit, electronic health records were searched to identify whether a prior diagnosis of a mood disorder was indicated. Previously assigned mood disorder diagnoses may have included bipolar disorders, disruptive mood dysregulation disorder, major depressive disorder, other specified

depressive disorder, or unspecified depressive disorder. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified in the "previously assigned diagnosis" section of these documents, and key words may have included notation of previous "disruptive mood dysregulation disorder" or "major depressive disorder" diagnoses. Previous assignment of a mood disorder diagnosis was coded as follows: 0 = no previous diagnosis of mood disorder; 1 = previous diagnosis of mood disorder. This was a binary type variable and selected based on its inclusion in prior investigations (as previously noted in the literature review).

Ever Assignment of Other Diagnosis – Mood Disorder. To determine whether a child or adolescent ever received a diagnosis of a mood disorder, electronic health records were reviewed to determine if a current or previous mood disorder diagnosis was assigned. This variable was created by combining information from the two prior variables ("Current Assignment of Other Diagnosis – Mood Disorder" and "Previous Assignment of Other Diagnosis – Mood Disorder") to assist with running planned statistical analyses. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified in either the "currently assigned diagnosis" of "previously assigned diagnosis" sections of these documents, and key words may have included notation of current or previous "major depressive disorder" or "disruptive mood dysregulation disorder" diagnoses. Ever assignment of mood disorder diagnosis was coded as follows: 0 = never diagnosis of mood disorder; 1 = ever diagnosis of

mood disorder. This was a binary type variable, and was included given its use in previous empirical studies (as indicated in the literature review).

Race of Child. Electronic health records were reviewed to determine the race of all infants, children, and adolescents seen by clinicians in the A&DD Clinic based on categories used in the most recent U.S. Census recording (U.S. Census Bureau, 2020). Information related to this factor was searched for and identified within the patient demographic "racial background" section of the electronic health record, and specific key words may have included "Black/African American" or "White/Caucasian." Race of the child was coded as follows: NA = information not available (if information regarding an individual's race was not reported in the electronic health record); 1 = White/Caucasian; 2 = Black/African American; 3 = Asian/Asian American; 4 = American Indian/Alaska Native; 5 = Native Hawaiian/Other Pacific Islander; 7 = Other Race (biracial, multiracial). This was a categorical type variable, and was chosen given its analysis in previous investigations (as described previously in the literature review).

Ethnicity of Child. Electronic health records were examined to determine the ethnicity of all infants, children, and adolescents seen by clinicians in the A&DD Clinic, again based on data from the recent U.S. Census (U.S. Census Bureau, 2020). Information related to this factor was searched for and identified within the patient demographic "ethnic background" section of the electronic health record, and specific key words may have included "Non-Hispanic/Latino" or "Hispanic/Latino.". Ethnicity of the child was coded as follows: 0 = Non-Hispanic/Latino; 1 = Hispanic/Latino. This was a categorical type variable and selected based on its inclusion in prior studies (as outlined in the literature review).

Race/Ethnicity of Child. Electronic health records were reviewed to determine the race/ethnicity of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. This variable was created by combining information from the two prior variables ("Race of Child" and "Ethnicity of Child") to assist with running planned descriptive analyses and was again based on categories used in the most recent U.S. Census recording (U.S. Census Bureau, 2020). Information related to this factor was searched for and identified within the patient demographic "racial/ethnic background" section of the electronic health record. Specific key words may have included "White/Caucasian, Non-Hispanic/Latino," "White/Caucasian, Hispanic/Latino," or "Asian/Asian American, Non-Hispanic/Latino." Combined race/ethnicity of the child was coded as follows: NA = information not available (if information regarding an individual's race was not reported in the electronic health record); 1 = White/Caucasian, Non-Hispanic/Latino; 2 = White/Caucasian, Hispanic/Latino; 3 = Black/African American, Non-Hispanic/Latino; 4 = Black/African American, Hispanic/Latino; 5 = Asian/Asian American, Non-Hispanic/Latino; 6 = Asian/Asian American, Hispanic/Latino; 7 = American Indian/Alaska Native, Non-Hispanic/Latino; 8 = American Indian/Alaska Native, Hispanic/Latino; 9 = Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino; 10 = Native Hawaiian/Other Pacific Islander, Hispanic/Latino; 11 = Other Race (biracial, multiracial), Non-Hispanic/Latino; 12 = Other Race (biracial, multiracial), Hispanic/Latino. This was a categorical type variable and chosen given its evaluation in previous research (as discussed in the literature review).

Alternative Race/Ethnicity of Child. Electronic health records were examined to determine the combined race/ethnicity of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. This variable was created to assist with running planned statistical analyses,

as many of the specific race/ethnicity classifications included above (for the "Race/Ethnicity of Child" variable) did not have a sufficient number of cases within each predetermined variable level. Information related to this factor was searched for and identified within the patient demographic "racial/ethnic background" section of the electronic health record. Specific key words for notation may have included "White/Caucasian, Non-Hispanic/Latino," "Black/African American, Non-Hispanic/Latino," or "Asian/Asian American, Non-Hispanic/Latino." Alternative race/ethnicity of the child was coded as follows: NA = information not available (if information regarding an individual's race was not reported in the electronic health record); 1 = White/Caucasian, Non-Hispanic/Latino; 2 = White/Caucasian, Hispanic/Latino; 3 = Black/African American, Non-Hispanic/Latino; 4 = Asian/Asian American, Non-Hispanic/Latino; 5 = Other (Black/African American, Hispanic/Latino; Asian/Asian American, Hispanic/Latino; American Indian/Alaska Native, Non-Hispanic/Latino; American Indian/Alaska Native, Hispanic/Latino; Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino; Native Hawaiian/Other Pacific Islander, Hispanic/Latino; Other Race (biracial, multiracial), Non-Hispanic/Latino; Other Race (biracial, multiracial), Hispanic/Latino). This was a categorical type variable, and was included based on its presence in previous empirical studies (as described previously in the literature review).

Sex of Child. Electronic health records were examined to determine the biological sex of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. Information related to this factor was searched for and identified within the patient demographic "biological sex" section of the electronic health record, and specific key words may have included "male" or "female" sex. Biological sex of the child was coded as follows: 0 = male sex; 1 = female sex.

This was a binary type variable and chosen given its inclusion in prior investigations (as outlined previously in the literature review).

Specific Primary Language of the Child. Electronic health records were reviewed to determine the specific primary language of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. Specific primary language of the child may have included English, Spanish, American Sign Language, Mandarin, Albanian, Arabic, or Cambodian languages. Information related to this factor was searched for and identified within the patient demographic "spoken language" section of the electronic health record, and key words for notation may have included "English," "Mandarin," or "Arabic." Specific primary language of the child was coded as follows: 0 = English language; 1 = Spanish language; 2 = American Sign Language; 3 = Mandarin; 4 = Albanian; 5 = Arabic; 6 = Cambodian. This was a categorical type variable, and was included based on its use in previous research studies (as described in the literature review).

General Primary Language of the Child. Electronic health records were examined to determine the general primary language of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. This variable was created by combining information included within the previous variable ("Specific Primary Language of the Child") to assist with running planned descriptive analyses. General primary language of the child may have included English language, Spanish language, or another language (American Sign Language, Mandarin, Albanian, Arabic, or Cambodian). Information related to this factor was searched for and identified within the patient demographic "spoken language" section of the electronic health record, and specific key words may have included "English" or "Spanish." General primary

language of the child was coded as follows: 0 = English language; 1 = Spanish language; 2 = another language (either American Sign Language, Mandarin, Albanian, Arabic, or Cambodian). This was a categorical type variable, and was selected based on its analysis in prior research (as noted in the literature review).

Binary Primary Language of the Child. Electronic health records were reviewed to determine the binary primary language of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. This variable was created to assist with running planned statistical analyses, as many of the detailed primary language classifications included above (for the "Specific Primary Language of the Child" and "General Primary Language of the Child" variables) did not have a sufficient number of cases within each predetermined variable level. Binary primary language of the child may have included English language or another language (either Spanish, American Sign Language, Mandarin, Albanian, Arabic, or Cambodian). Information related to this factor was searched for and identified within the patient demographic "spoken language" section of the electronic health record, and specific key words may have included "English," "American Sign Language," or "Albanian." Binary primary language of the child was coded as follows: 0 = English language; 1 = another language (either Spanish, American Sign Language, Mandarin, Albanian, Arabic, or Cambodian). This was a binary type variable and chosen given its inclusion in previous studies (as discussed previously in the literature review).

Child's Age at Time of Clinic Referral. Information from electronic health records was reviewed to determine the infant, child, or adolescent's chronological age at the time of referral to the A&DD Clinic. Data for this factor was identified through the official log of provider/patient contact calendar dates, and the numeric age was specifically selected from the

date in which the A&DD Clinic received an official referral from the referring healthcare provider. Chronological age was fully written out (in terms of year and month) and recorded as such. This was a continuous type variable, and was included as an exploratory factor to more fully understand the pathway toward potential diagnosis.

Child's Age at Time of Initial Clinic Contact with Family. Information from electronic health records was examined to determine the infant, child, or adolescent's chronological age at the time of initial A&DD Clinic contact with the family for scheduling or referral clarification purposes. Data for this factor was identified through the official log of provider/patient contact calendar dates, and the numeric age was specifically selected from the date in which the A&DD Clinic initiated initial contact with the patient's family. Chronological age was fully written out (in terms of year and month) and recorded as such. This was a continuous type variable and selected as a novel factor to more clearly comprehend the service provision process.

Child's Age at Time of Clinic Intake Interview Appointment. Information from electronic health records was reviewed to determine the infant, child, or adolescent's chronological age at the time of the initial clinic intake interview appointment in the A&DD Clinic. Data for this factor was identified through the official log of provider/patient contact calendar dates, and the numeric age was specifically selected from the date in which the patient's family completed a diagnostic intake interview with a clinician in the A&DD Clinic. Chronological age was fully written out (in terms of year and month) and recorded as such. This was a continuous type variable, and was included as an exploratory factor to better understand the service provision pathway.

Child's Age at Time of Clinic Assessment Appointment(s). Information from electronic health records was examined to determine the infant, child, or adolescent's chronological age at the time of the assessment appointment(s) in the A&DD Clinic. For any individuals who had more than one assessment appointment, the child's age at the latest appointment date in time was recorded. Data for this factor was identified through the official log of provider/patient contact calendar dates, and the numeric age was specifically selected from the date in which the patient's family completed the latest assessment appointment with a clinician in the A&DD Clinic. Chronological age was fully written out (in terms of year and month) and recorded as such. This was a continuous type variable and chosen as a novel factor to more fully comprehend the service provision process.

Child's Age at Time of Clinic Feedback. Information from electronic health records was reviewed to determine the infant, child, or adolescent's chronological age at the time of the diagnostic feedback session in the A&DD Clinic. Data for this factor was identified through the official log of provider/patient contact calendar dates, and the numeric age was specifically selected from the date in which the patient's family completed the final diagnostic feedback session with a clinician in the A&DD Clinic. Chronological age was fully written out (in terms of year and month) and recorded as such. This was a continuous type variable, and was selected as an exploratory factor to better understand the pathway toward potential diagnosis.

Reported Enrollment in Early Intervention Services. Information from electronic health records was searched to determine whether infants, children, or adolescents were enrolled in early intervention (Part C) services prior to diagnosis. Enrollment in these services may have occurred at any time. Information related to this factor was searched for and identified within the

initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior educational services" or "prior therapeutic support services" sections of these documents, and key phrases may have included "Birth to Three enrollment" or "early intervention services." Reported enrollment in early intervention services was coded as follows: 0 = no reported enrollment in early intervention services; 1 = reported enrollment in early intervention services. This was a binary type variable, and was included as an exploratory factor given its potential relationship to timing and match of referral for diagnostic evaluation.

Reported Enrollment in Early Childcare Services. Information from electronic health records was reviewed to determine whether infants, children, or adolescents were enrolled in early childcare services prior to diagnosis. Enrollment in these services may have occurred at any time, and early childcare services may have included accredited childcare programs, non-accredited childcare programs, home-based childcare programs, or center-based childcare programs. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior educational services" or "prior therapeutic support services" sections of these documents, and key phrases for notation may have included "center-based childcare program" or "in-home childcare services." Reported enrollment in early childcare services was coded as follows: 0 = no reported enrollment in early childcare services; 1 = reported enrollment in early childcare services. This was a binary type variable, and

was selected as a novel factor based on its possible link to match and timing of evaluation referral.

Reported Enrollment in Head Start/Early Head Start Services. Information from electronic health records was examined to determine whether infants, children, or adolescents were enrolled in Head Start and/or Early Head Start services prior to diagnosis. Enrollment in these services may have occurred at any time. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior educational services" or "prior therapeutic support services" sections of these documents, and key phrases may have included "Head Start enrollment" or "Early Head Start services." Reported enrollment in Head Start/Early Head Start services was coded as follows: 0 = no reported enrollment in Head Start/Early Head Start services; 1 = reported enrollment in Head Start/Early Head Start services. This was a binary type variable, and was included as an exploratory factor given its potential relationship to referral for diagnostic evaluation.

Reported Enrollment in Supplemental Therapeutic Support Services. Information from electronic health records was searched to determine whether infants, children, or adolescents were enrolled in any supplemental therapeutic support services prior to diagnosis. Access to these services may have occurred at any time and may have included services such as speech-language therapy, occupational therapy, physical therapy, or psychological intervention. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) was not counted as "reported

enrollment in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior therapeutic support services" section of these documents, and key phrases for notation may have included "speech therapy" or "physical therapy." Reported enrollment in supplemental therapeutic support services was coded as follows: 0 = no reported enrollment in supplemental therapeutic support services; 1 = reported enrollment in supplemental therapeutic support services. This was a binary type variable and selected based on its inclusion in prior studies (as previously outlined in the literature review).

Reported Enrollment in Supplemental Therapeutic Support Services – Speech-Language Therapy. Following review of information related to potential enrollment in supplemental therapeutic support services, further examination determined whether infants, children, or adolescents were enrolled in speech-language therapy services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) was not counted as "reported enrollment in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior therapeutic support services" section of these documents, and key phrases for notation may have included "speech therapy" or "speech-

language intervention." Enrollment in speech-language therapy services was coded as follows: 0 = no reported enrollment in speech-language therapy services; 1 = reported enrollment in speech-language therapy services; NA = not applicable (for those who were not reportedly enrolled in any supplemental therapeutic support services). This was a binary type variable and included given its use in previous empirical investigations (as indicated in the literature review).

Reported Enrollment in Supplemental Therapeutic Support Services – Occupational Therapy. Following review of information related to potential enrollment in supplemental therapeutic support services, further examination determined whether infants, children, or adolescents were enrolled in occupational therapy services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) was not counted as "reported enrollment in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This data was specifically identified under the "prior therapeutic support services" section of these documents, and key phrases for notation may have included "occupational therapy" or "treatment for fine motor skills." Enrollment in occupational therapy services was coded as follows: 0 = no reported enrollment in occupational therapy services; 1 = reported enrollment in occupational therapy services; NA = not applicable (for those who were not reportedly enrolled in any supplemental therapeutic support services). This was a binary type variable, and was chosen based on its analysis in previous research (as previously noted in the literature review).

Reported Enrollment in Supplemental Therapeutic Support Services – Physical Therapy. Following review of information related to potential enrollment in supplemental therapeutic support services, further examination determined whether infants, children, or adolescents were enrolled in physical therapy services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) was not counted as "reported enrollment in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior therapeutic support services" section of these documents, and key phrases for notation may have included "physical therapy" or "intervention for gross motor skills." Enrollment in physical therapy services was coded as follows: 0 = no reported enrollment in physical therapy services; 1 = reported enrollment in physical therapy services; NA = not applicable (for those who were not reportedly enrolled in any supplemental therapeutic support services). This was a binary type variable, and was selected given its presence in prior investigations (as indicated in the literature review).

Reported Enrollment in Supplemental Therapeutic Support Services – Psychological Intervention. Following review of information related to potential enrollment in supplemental therapeutic support services, further examination determined whether infants, children, or adolescents were enrolled in psychological intervention services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time, and potential services

may have included cognitive behavioral intervention, EIBI, behavioral intervention, applied behavior analysis treatment, play-based therapy, or counseling intervention. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) was not counted as "reported enrollment in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior therapeutic support services" section of these documents, and key phrases for notation may have included "counseling," "in-home applied behavior analysis treatment," or "behavioral therapy." Enrollment in psychological intervention services was coded as follows: 0 = no reported enrollment in psychological intervention services; 1 = reported enrollment in psychological intervention services; NA = not applicable (for those who were not reportedly enrolled in any supplemental therapeutic support services). This was a binary type variable and included given its analysis in previous research (as noted previously in the literature review).

Reported Receipt of Early Special Education/Special Education Services.

Information from electronic health records was searched to determine whether children or adolescents were enrolled in any early special education (early childhood) or special education services through Part B of IDEIA (2004) in the public education system prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an evaluation (but not qualifying or not yet receiving access to services) was not counted as "reported receipt of services" here. Information related to this factor was searched for and

identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior educational services" sections of these documents, and key phrases may have included "special education," "early childhood special education," or "individualized education program." Reported receipt of early special education or special education services was coded as follows: 0 = no reported receipt of early special education or special education services; 1 = reported receipt of early special education or special education services. This was a binary type variable, and was chosen based on its evaluation in previous studies (as described in the literature review).

Reported Receipt of Early Special Education/Special Education Services – Primary Indicated IDEIA Disability Classification. Following review of information related to potential receipt of early special education or special education services, further examination determined the primary disability classification that children were assigned in the public education system under Part B of IDEIA (2004). Information related to this factor was searched for and identified within the initial screening phone call notes, scanned individualized education program (IEP) documentation, or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. If available, this data was identified under the "prior educational services" sections of these documents, and key phrases may have included "emotional behavioral disturbance," "speech or language impairment," or "other health impairment." Primary IDEIA disability classification was coded as follows: 0 = IDEIA disability classification not reported (for individuals who reportedly received early special education or special education services, but the specific disability

classification was not included in the electronic health record); 1 = ASD; 2 = ID; 3 = specific learning disability (SLD); 4 = other health impairment (OHI); 5 = emotional behavioral disturbance (EBD); 6 = speech or language impairment (SLI); 7 = deafness; 8 = hearing impairment; 9 = significant developmental delay (SDD); NA = not applicable (for those who were not reported to have received early special education or special education services). This was a categorical type variable, and was selected as an exploratory factor given its relationship to receipt of special education services.

Reported Receipt of Early Special Education/Special Education Services – Reported Participation in Speech-Language Therapy Services Through School System. Following review of information related to the potential receipt of early special education or special education services, further examination determined whether children or adolescents participated in speech-language therapy services through the public school system. Access to these services may have occurred at any time. Participating in an evaluation (but not yet receiving access to services) was not counted as "reported participation in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes, scanned IEP documentation, or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior educational services" sections of these documents, and key phrases may have included "speech therapy" or "speech-language intervention." Reported participation in speech-language therapy services through the school system was coded as follows: 0 = no reported participation in speech-language therapy services; 1 = reported participation in speech-language therapy services; NA = not applicable (for those

who did not reportedly receive early special education or special education services). This was a binary type variable and included as a novel factor based on its relationship to receiving special education supports.

Reported Receipt of Early Special Education/Special Education Services – Reported Participation in Occupational Therapy Services Through School System. Following review of information related to the potential receipt of early special education or special education services, further examination determined whether children or adolescents participated in occupational therapy services through the public school system. Access to these services may have occurred at any time. Participating in an evaluation (but not yet receiving access to services) was not counted as "reported participation in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes, scanned IEP documentation, or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This data was specifically identified under the "prior educational services" sections of these documents, and key phrases may have included "occupational therapy" or "treatment for fine motor skills." Reported participation in occupational therapy services through the school system was coded as follows: 0 = no reported participation in occupational therapy services; 1 = reported participation in occupational therapy services; NA = not applicable (for those who did not reportedly receive early special education or special education services). This was a binary type variable, and was chosen as an exploratory factor given its relation to receipt of special education supports.

Reported Receipt of Early Special Education/Special Education Services – Reported Participation in Physical Therapy Services Through School System. Following review of information related to the potential receipt of early special education or special education services, further examination determined whether children or adolescents participated in physical therapy services through the public school system. Access to these services may have occurred at any time. Participating in an evaluation (but not yet receiving access to services) was not counted as "reported participation in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes, scanned IEP documentation, or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "prior educational services" sections of these documents, and key phrases may have included "physical therapy" or "treatment for gross motor skills." Reported participation in physical therapy services through the school system was coded as follows: 0 = no reported participation in physical therapy services; 1 = reported participation in physical therapy services; NA = not applicable (for those who did not reportedly receive early special education or special education services). This was a binary type variable and included as a novel factor given its relationship to receiving special education services.

Reported Receipt of Early Special Education/Special Education Services – Reported Participation in Psychological Intervention Services Through School System. Following review of information related to the potential receipt of early special education or special education services, further examination determined whether children or adolescents participated in psychological intervention services through the public school system. Access to these services

may have occurred at any time, and potential services may have included cognitive behavioral intervention, applied behavior analysis treatment, behavioral intervention and supports, or counseling intervention. Participating in an evaluation (but not yet receiving access to services) was not counted as "reported participation in services" here. Information related to this factor was searched for and identified within the initial screening phone call notes, scanned IEP documentation, or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This data was specifically identified under the "prior educational services" sections of these documents, and key phrases may have included "services with the school psychologist" or "counseling supports." Reported participation in psychological intervention services through the school system was coded as follows: 0 = no reported participation in psychological intervention services; 1 = reported participation in psychological intervention services; NA = not applicable (for those who did not reportedly receive early special education or special education services). This was a binary type variable, and was selected as an exploratory factor given its association with receiving special education.

Overall Risk Status Indicated for ASD Disorder-Specific Screening Tool Reported. Following determination of whether an infant or child was reportedly administered an ASD disorder-specific screening measure (like the M-CHAT-R/F), the electronic health record was examined to determine the overall risk status indicated for the reported screening measure. Information related to this factor was searched for and identified within the "screening conduction" section of the referring healthcare provider's referral form, the initial screening phone call notes, or the visit progress notes and/or diagnostic evaluation reports of psychology or

developmental pediatric clinicians from the A&DD Clinic. Specific key words for notation may have included “low risk for ASD” or “high risk for ASD” on the M-CHAT-R/F screening measure. Overall risk status was coded as follows: 0 = risk for ASD not reported; 1= low risk for ASD; 2 = moderate risk for ASD; 3 = high risk for ASD; NA = not applicable (if an ASD disorder-specific screening measure was not reported in the electronic health record). This was a categorical type variable and included based on its association with previous research investigations (as previously indicated in the literature review).

Match of Referral and Associated Diagnosis. Information from electronic health records was reviewed to determine the match between the indicated referral concern and subsequent diagnosis assigned for infants, children, and adolescents seen by clinicians in the A&DD Clinic. Indicated referral concerns by referring healthcare providers may have included ASD, ID, or DD. Subsequent diagnoses assigned may have included ASD, ID, global developmental delay, speech-language disorder, genetic disorder/difference, ADHD, anxiety, obsessive compulsive, or adjustment disorder, or mood disorder. Information related to this factor was searched for and identified within the referring healthcare provider’s clinical referral and the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this information was identified under the “referral concern” and “currently assigned diagnosis” sections of these documents. Key words for the referral may have included “autism” or “developmental delay,” and key phrases for the subsequent diagnosis may have included “autism spectrum disorder,” “ADHD – combined presentation,” or “mixed expressive-receptive language delay.” Because this study was concerned with understanding the pathway towards referral for

ASD and subsequent diagnosis of ASD, outlined variables were situated within this frame of reference. Therefore, match of referral and associated diagnosis was coded as follows: 0 = referral for ASD and subsequent diagnosis of ASD; 1 = referral for another disorder and subsequent diagnosis of ASD; 2 = referral for ASD and no subsequent diagnosis of ASD (either diagnosis of another disorder or no diagnosis); 3 = referral for another disorder and no subsequent diagnosis of ASD (either diagnosis of another disorder or no diagnosis). This was a categorical type of variable. If no subsequent diagnosis of ASD was made, it was specifically recorded whether the individual received a diagnosis of another disorder (and what the disorder was) or did not receive a diagnosis at all. For any situations in which an individual received a diagnosis of ASD and a diagnosis of another disorder (ID, ADHD, etc.), this was recorded as a subsequent diagnosis of ASD. This factor was the dependent variable for Research Question #1.

Alternative Match of Referral and Associated Diagnosis. Information from electronic health records was reviewed to determine the match between the indicated referral concern and subsequent diagnosis assigned for infants, children, and adolescents seen by clinicians in the A&DD Clinic. Again, indicated referral concerns by referring healthcare providers may have included ASD, ID, or DD, and subsequent diagnoses assigned may have included ASD, ID, global developmental delay, speech-language disorder, genetic disorder/difference, ADHD, anxiety, obsessive compulsive, or adjustment disorder, or mood disorder. This variable was created to assist with running planned statistical analyses, as two of the "Match of Referral and Associated Diagnosis" classifications included above (specifically "1 = referral for another disorder and subsequent diagnosis of ASD" and "2 = referral for ASD and no subsequent diagnosis of ASD") often did not have a sufficient number of cases within each predetermined

variable level. Alternative match of referral and associated diagnosis was coded as follows: 0 = match (referral for ASD and subsequent diagnosis of ASD); 1 = unmatched (referral for another disorder and subsequent diagnosis of ASD or referral for ASD and no subsequent diagnosis of ASD); 2 = other (referral for another disorder and no subsequent diagnosis of ASD). Information related to this factor was searched for and identified within the referring healthcare provider's clinical referral and the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This information was specifically identified under the "referral concern" and "currently assigned diagnosis" sections of these documents. Key words for the referral may have included "autism" or "intellectual disability," and key phrases for the subsequent diagnosis may have included "autism spectrum disorder," "ADHD – combined presentation," or "mixed expressive-receptive language delay." As previously mentioned, because this study was concerned with understanding the pathway towards referral for ASD and subsequent diagnosis of ASD, outlined variables were situated within this frame of reference. This factor was the alternative dependent variable for Research Question #1, and was a categorical type of variable.

No Subsequent Diagnosis of ASD. If no subsequent diagnosis of ASD was made for the previous dependent variable ("match of referral and associated diagnosis"), it was specifically recorded whether that individual received a diagnosis of another disorder (and what the disorder was), received more than one other disorder diagnoses (and what those disorders were), or did not receive a diagnosis at all. Information related to this factor was searched for and identified within the "currently assigned diagnosis" section of visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric

clinicians from the A&DD Clinic. Specifically, key words for notation may have included "ADHD – combined presentation," "global developmental delay," or "intellectual disability" diagnoses. No subsequent diagnosis of ASD was coded as follows: NA = not applicable (if the child received a subsequent diagnosis of ASD); 1 = no new diagnosis received; 2 = diagnosis of ID; 3 = diagnosis of global developmental delay; 4 = diagnosis of speech-language disorder; 5 = diagnosis of genetic disorder/difference; 6 = diagnosis of ADHD; 7 = diagnosis of anxiety disorder/obsessive compulsive disorder/adjustment disorder; 8 = diagnosis of mood disorder; 9 = diagnosis of ID and speech-language disorder; 10 = diagnosis of ADHD and speech-language disorder; 11 = diagnosis of ADHD and global developmental delay; 12 = diagnosis of global developmental delay and speech-language disorder; 13 = diagnosis of mood disorder and speech-language disorder; 14 = diagnosis of anxiety disorder/obsessive compulsive disorder/adjustment disorder and speech-language disorder. This was a categorical type variable, and was included to provide additional context regarding which (if any) diagnoses a child may have otherwise received.

Timeliness of Referral to the Diagnostic Clinic. Information from electronic health records was examined to determine the timeliness of referral from referring healthcare providers for infants, children, and adolescents seen in the A&DD Clinic. Because this study was concerned with understanding the timeliness of referral in terms of referral for children at or before three years of age compared to referral for children after three years of age, outlined variables were situated within this frame of reference. Children referred under or up to three years and eleven months of age (47 months) were considered as a "timely referral to the clinic." This dichotomy was chosen based on considerations regarding age for qualification and

participation in early intervention services (for which children are eligible to receive up to three years of age), as well as three years being an age commonly associated with ASD-specific screening measures. Data for this factor was identified through the official log of provider/patient contact calendar dates, and the numeric age was specifically selected from the date in which the A&DD Clinic received an official referral from the referring healthcare provider. Timeliness of referral to the diagnostic clinic was coded as follows: 0 = referral at or before individual is three years of age; 1 = referral after individual is three years of age. This factor was the dependent variable for Research Question #2 and a binary type variable.

Family-Related Factors

Caregiver-Reported Age of Initial Concern. Information from electronic health records was reviewed to determine the initial age at which caregivers reportedly became concerned about their infant, child, or adolescent's development. Data related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this data was identified under the "caregiver-reported concerns" or "background information" sections of these documents, and key phrases for notation may have included "initial concerns were expressed at 18 months of age" or "caregiver reported initial developmental concerns at 24 months." Chronological age of initial concern was fully written out (in terms of year and month) and recorded as such. A code of "NA" indicated that this information was not reported in the electronic health record. This was a continuous type variable, and was selected based on its use in previous studies (as outlined in the literature review).

Specific Caregiver-Reported Behavior of Initial Concern. Information from electronic health records was searched to determine the specific initial behavior which reportedly raised concern for caregivers regarding their infant, child, or adolescent's development. Potential specific behaviors of initial concern may have included delays or differences in speech/language skills; language regression; delays or differences in motor skills (including fine and/or gross motor skills); delays or differences across global development (including speech/language skills, fine motor skills, and/or gross motor skills); global developmental regression; odd communication skills (including challenges with responding to name and/or engaging in reciprocal conversation with others); lack of social interaction (including difficulties with social engagement and/or play-related skills); lack of eye contact; restrictive and repetitive behaviors (including sensory differences and/or challenges with intense interests, preferences, or preoccupations); challenging behaviors (including difficulties with overactivity/hyperactivity, frequent crying and/or avoidance behaviors, physical aggression, and/or tantrum-like behaviors); medical complications (including challenges with feeding, sleeping, and/or memory skill performance); or more than one initial behavior of concern reported (including delays in speech/language and motor skills, delays in speech/language skills and challenging behaviors, delays in speech/language skills and odd social communication skills, delays in motor skills and challenges with feeding, and/or global developmental regression and challenging behaviors). . Information related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. This information was specifically identified under the "caregiver-reported concerns" or "background

information" sections of these documents, and key phrases for notation may have included concerns related to "delays in speech and language development," "lack of eye contact," "physical aggression," "sleep-related concerns," or "challenges with social interaction." Specific caregiver-reported behavior of initial concern was coded as follows: NA = not applicable (if caregiver-reported behavior of initial concern was not reported in the electronic health record); 1 = delays or differences in speech/language skills; 2 = language regression; 3 = delays or differences in fine and/or gross motor skills; 4 = delays or differences across global development; 5 = global developmental regression; 6 = odd social communication skills; 7 = lack of social interaction; 8 = lack of eye contact; 9 = restrictive and repetitive behaviors; 10 = challenging behaviors; 11 = medical complications; 12 = more than one initial behavior of concern. This was a categorical type variable and chosen given its inclusion in prior research (as previously described in the literature review).

General Caregiver-Reported Behavior of Initial Concern. Information from electronic health records was examined to determine the general initial behavior which reportedly raised concerns for caregivers regarding their infant, child, or adolescent's development. This variable was created to assist with running planned statistical analyses, as many of the detailed behavior of initial concern classifications included above (for the "Specific Caregiver-Reported Behavior of Initial Concern" variable) did not have a sufficient number of cases within each predetermined variable level. Potential general behaviors of initial concern may have included delays, differences, or regression in speech/language skills; delays, differences, or regression in motor skills (including fine motor and/or gross motor skills) or global developmental skills (including speech/language, fine motor, and/or gross motor skills); social communication differences

(including odd communication skills, lack of social interaction, and/or lack of eye contact); restrictive and repetitive behaviors (including sensory differences and/or challenges with intense interests, preferences, or preoccupations); challenging behaviors (including difficulties with overactivity/hyperactivity, frequent crying and/or avoidance behaviors, physical aggression, and/or tantrum-like behaviors); medical complications (including challenges with feeding, sleeping, and/or memory skill performance); or more than one initial behavior of concern reported (including delays in speech/language and motor skills, delays in speech/language skills and challenging behaviors, delays in speech/language skills and odd social communication skills, delays in motor skills and challenges with feeding, and/or global developmental regression and challenging behaviors). Data related to this factor was searched for and identified within the initial screening phone call notes or the visit progress notes and/or diagnostic evaluation reports of psychology, speech-language pathology, or developmental pediatric clinicians from the A&DD Clinic. Specifically, this information was identified under the "caregiver-reported concerns" or "background information" sections of these documents, and key phrases for notation may have included concerns related to "delays in speech and language development," "lack of eye contact," "physical aggression," "sleep-related concerns," or "challenges with social interaction." General caregiver-reported behavior of initial concern was coded as follows: NA = not applicable (if caregiver-reported behavior of initial concern was not reported in the electronic health record); 1 = delays, differences, or regression in speech/language skills; 2 = delays, differences, or regression in motor skills or global developmental skills; 3 = social communication differences; 4 = restrictive and repetitive behaviors; 5 = challenging behaviors; 6 = medical complications; 7 = more than one initial behavior of concern. This was a categorical

type variable and selected given its use in prior investigations (as outlined in the literature review).

Family Insurance Type. Information recorded in electronic health records was reviewed to determine the insurance type of families receiving diagnostic services from clinicians in the A&DD Clinic. Potential insurance types may have included public health insurance coverage (including Medicaid Wisconsin, Medicaid Illinois, Mercycare Medicaid, BadgerCare Plus, Quartz BadgerCare, TRICARE/Champus, Meridian Health, and Meridian Health Plan) or private health insurance coverage (including Anthem Blue Cross Blue Shield, Blue Cross Blue Shield of Illinois, United Healthcare, UMR United Healthcare, Aetna, Humana, Alliance Humana, Quartz Community Network, Quartz University of Wisconsin Health, Quartz One, Quartz, Quartz Unity, Molina Healthcare, Auxiant, Alliance Auxiant, Managed Health Services, Medical Associates, Health Partners, WEA Insurance Trust, Community Care Program for Financial Assistance, Security Health Plan, Alliance Professional Benefit, Dean Health Plan, Deancare, Mercycare, Unity Health Plan, Cigna, Cigna Open Access, Group Health Cooperative Health Plan, Network Health Plan, WPS Health Plan, and Aspirus Arise Health Plan). Data related to this factor was searched for and identified within the "family insurance type" section of the initial screening phone call notes or patient demographic information section of the electronic health record. Specific key words for notation may have included "Medicaid Wisconsin," "Anthem Blue Cross Blue Shield," "Unity Health Plan," and "Quartz One" insurance types. Family insurance type was coded as follows: 0 = public health insurance; 1 = private health insurance. This was a binary type variable, and was included as an exploratory factor in the study given its potential association with socioeconomic status.

Household Zip Code. Information from electronic health records was examined to determine the household zip code of families at the time of referral and diagnosis. This factor served as a proxy for geographic location. Household zip codes were fully written out and recorded upon initiation of record examination. Then, upon later review, zip codes were grouped and coded based on similarity in health service areas (related to healthcare services and surrounding municipalities) identified through the *Wisconsin Area Health Education Center*s service area groupings (Wisconsin Area Health Education Centers, 2015). Potential household zip code groupings may have included metro health service area (an area in which greater than 50% of the population lives in an urbanized area [densely developed territory of 50,000 people or more] as defined by the 2010 United States Census), urban health service area (an area in which less than 50% of the population lives in an urbanized area, but greater than 60% of the population lives in either a densely settled urbanized area [see definition above] or urban cluster area [densely developed territory of at least 2,500 people but less than 50,000 people] as defined by the 2010 United States Census), mixed health service area (an area in which 40-60% of the population lives in either a densely settled urbanized area or urban cluster area [see definitions above] as defined by the 2010 United States Census), rural health service area (an area in which less than 40% of the population lives in a densely settled area as defined by the 2010 United States Census), or out of state health service area (an area outside the state of Wisconsin). Data related to this factor was searched for and identified within the patient demographic "home mailing address" information section of the electronic health record, and a wide range of specific zip codes were extracted and coded. Household zip code was coded as follows: 0 = metro health service area; 1 = urban health service area; 2 = mixed health service area; 3 = rural health service

area; 4 = out of state health service area. This was a categorical type variable, and was chosen given its evaluation in previous research studies (as previously described in the literature review).

Referring Healthcare Provider-Related Factors

Screening Measure Type Reported by Referring Healthcare Provider. Information from electronic health records was reviewed to determine if developmental screening (like the ASQ-3) or ASD disorder-specific screening (like the M-CHAT-R/F) was reported by the referring healthcare provider prior to referral of infants and children to the A&DD Clinic. Types of screening may have included no reported use of screening measures, reported use of developmental screening, reported use of disorder-specific screening for ASD, or reported use of both developmental screening and disorder-specific screening for ASD. Data related to this factor was searched for and identified within the "screening conduction" section of the referring healthcare provider's referral form, the initial screening phone call notes, or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specific key words for notation included "developmental screening used" or "ASD screening conducted." Screening measure type reported by the referring healthcare provider was coded as follows: NA = no screening measure reported; 1 = only developmental screening measure reported; 2 = only disorder-specific screening measure for ASD reported; 3 = both developmental screening measure and disorder-specific screening measure for ASD reported. This was a categorical type variable, and was selected based on its evaluation in prior investigations (as previously described in the literature review).

Name of Developmental Screening Tool Reported. Following review of information related to the type of screening measure reported, electronic health records were examined to determine the name of the developmental screening tool reported for the referred infant or child. Developmental screening tools may have included the *Ages and Stages Questionnaire, Third Edition* (ASQ-3; Squires & Bricker, 2009) or the *Developmental Assessment of Young Children, Second Edition* (DAYC-2; Voress et al., 2012). Information related to this factor was searched for and identified within the "screening conduction" section of the referring healthcare provider's referral form, the initial screening phone call notes, or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specific key words for notation included "ASQ-3 used" or "DAYC-2 completed." Name of developmental screening tool reported was coded as follows: NA = not applicable (for cases in which use of screening tools were not reported or information regarding the name of the developmental screening tool was not available); 1 = ASQ-3; 2 = DAYC-2. This was a categorical type variable, and was included as a novel factor given its association with type of screening conducted by the referring healthcare provider.

Name of ASD Disorder-Specific Screening Tool Reported. Following review of information related to the type of screening measure indicated, electronic health records were examined to determine the name of the ASD disorder-specific screening tool reported for the referred infant or child. ASD disorder-specific screening tools may have included the *Modified Checklist for Autism in Toddlers, Revised with Follow-Up* (M-CHAT-R/F; Robins et al., 2009). Information related to this factor was searched for and identified within the "screening conduction" section of the referring healthcare provider's referral form, the initial screening

phone call notes, or the visit progress notes and/or diagnostic evaluation reports of psychology or developmental pediatric clinicians from the A&DD Clinic. Specific key words for notation included "M-CHAT-R/F used" or "M-CHAT-R/F administered." Name of ASD disorder-specific screening tool reported was coded as follows: NA = not applicable (for cases in which use of screening tools were not reported or information regarding the name of the ASD disorder-specific screening tool was not available); 1 = M-CHAT-R/F. This was a binary type variable, and was chosen as an exploratory factor based on its relationship to type of screening conducted by the referring provider.

Practice Type of Referring Healthcare Provider. Information from electronic health records was reviewed to determine the specific practice type in which the referring healthcare provider worked. Practice setting types may have included pediatric primary care practice, family medicine primary care practice, or pediatric specialty care practice (including specialty practice in developmental pediatrics, psychiatry, rehabilitation medicine, neurology, complex care, genetics, infectious disease, otolaryngology, neurological surgery, endocrinology, or metabolic disorders). Data related to this factor was searched for and identified within the "provider practice specialty area" section of the referring healthcare provider's referral form or the referring healthcare provider demographic information section of the electronic health record. Specific key phrases for notation may have included "pediatric primary care," "pediatric rehabilitative medicine," "family medicine primary care," or "pediatric and adolescent psychiatry." Practice type of the referring healthcare provider was coded as follows: NA = not applicable (if practice type of the referring healthcare provider was not reported); 1 = primary care pediatric practice type; 2 = primary care family medicine practice type; 3 = specialty care

pediatric practice type. This was a categorical type variable, and was included as an exploratory factor given its potential association with referring healthcare provider practices and training.

Clinical Practice Zip Code of Referring Healthcare Provider. Information from electronic health records was examined to determine the clinical practice zip code of the referring healthcare provider at the time of referral to the A&DD Clinic. This factor served as a proxy for geographic location. Clinical practice zip codes were fully written out and recorded upon initiation of record examination. Then, upon later review, zip codes were grouped and coded based on similarity in health service areas (related to healthcare services and surrounding municipalities) identified through the *Wisconsin Area Health Education Center*s service area groupings (Wisconsin Area Health Education Centers, 2015). Potential clinical practice zip code groupings may have included metro health service area (an area in which greater than 50% of the population lives in an urbanized area [densely developed territory of 50,000 people or more] as defined by the 2010 United States Census), urban health service area (an area in which less than 50% of the population lives in an urbanized area, but greater than 60% of the population lives in either a densely settled urbanized area [see definition above] or urban cluster area [densely developed territory of at least 2,500 people but less than 50,000 people] as defined by the 2010 United States Census), mixed health service area (an area in which 40-60% of the population lives in either a densely settled urbanized area or urban cluster area [see definitions above] as defined by the 2010 United States Census), rural health service area (an area in which less than 40% of the population lives in a densely settled area as defined by the 2010 United States Census), or out of state health service area (an area outside the state of Wisconsin). Data related to this factor was searched for and identified within the “practice mailing address” section of the

referring healthcare provider's referral form or the referring healthcare provider demographic information section of the electronic health record, and a wide range of specific zip codes were extracted and coded. Clinical practice zip code of the referring healthcare provider was coded as follows: 0 = metro health service area; 1 = urban health service area; 2 = mixed health service area; 3 = rural health service area; 4 = out of state health service area. This was a categorical type variable and selected as a novel factor based on its possible relationship to clinical practice and training of referring healthcare professionals.

Professional Role Type of Referring Healthcare Provider. Information from electronic health records was reviewed to determine the specific professional role type of the referring healthcare provider. Professional role types may have included being a Doctor of Medicine (MD) provider, a Doctor of Osteopathy (DO) provider, a Nurse Practitioner (NP) provider, or a Physician Assistant (PA) provider. Data related to this factor was searched for and identified within the "licensure" section of the referring healthcare provider's referral form or the referring healthcare provider demographic information section of the electronic health record. Specific key words for notation may have included "MD," "DNP," or "PA-C." Professional role type of the referring healthcare provider was coded as follows: 0 = MD provider; 1 = DO provider; 2 = NP provider; 3 = PA provider. This was a categorical type variable, and was included as an exploratory factor given its potential association with clinical training of referring healthcare providers.

Chief Concern Listed on Referral Form by Referring Healthcare Provider. Information from electronic health records was examined to determine the chief concern listed on the referral form submitted to the A&DD Clinic by the referring healthcare provider. Chief

referral concerns may have included ASD, ID, or DD (which includes speech-language delay, motor delay, and/or global developmental delay). Data related to this factor was searched for and identified within the "referral concern" section of the referring healthcare provider's referral form. Specific key words may have included "autism," "intellectual disability," or developmental delays." Chief concern listed on the referral form was coded as follows: 0 = ASD chief concern; 1 = ID chief concern; 2 = DD chief concern. This was a categorical type variable, and was included to specify which concerns were chiefly reported by the referring healthcare professional.

Data Analysis

Statistical Analysis

Planned statistical analysis of the extracted clinical health data included descriptive summary statistics of demographic variables and informational factors. Measures of central tendency (including mean and median) and measures of variability (including standard deviation [SD] and range) were chosen to summarize continuous variables, and measures of frequency (including frequency count and percentage) were utilized to summarize binary and categorical variables.

In order to answer sub-questions associated with Research Question #1, a series of chi-square tests of independence and multinomial logistic regression analyses were conducted to determine which child-related, family-related, and referring healthcare provider-related factors (independent variables) were individually and interactionally associated with referral for ASD and subsequent diagnosis of ASD (dependent variable). For all chi-square tests of independence, two-way contingency tables were constructed to evaluate whether each of the categorical or

binary independent variables (child-related, family-related, and referring healthcare provider-related factors) had a statistically significant effect on levels of the categorical dependent variable ("Match of Referral and Associated Diagnosis"). For situations in which the sample size was not large enough for the "referral for another disorder and subsequent diagnosis of ASD" and "referral for ASD and no subsequent diagnosis of ASD" levels of the original dependent variable to meet assumptions of the chi-square test of independence (at least five cases per chi-square contingency table cell), additional chi-square analyses were run with an alternative version of the dependent variable ("Alternative Match of Referral and Associated Diagnosis"). As previously outlined in the methods section, this alternative dependent variable specifically combined two levels of the original dependent variable into one "unmatched" referral and diagnosis level. Given that multiple tests were being conducted, statistical correction was applied to minimize the potential for false discovery rate. To do so, the Benjamini-Hochberg correction procedure (Benjamini & Hochberg, 1995) was applied to all individual chi-square analyses, and all individual analyses and corrected analyses were directly compared and reported. Multinomial logistic regression analyses were used to predict the categorical dependent variable ("Match of Referral and Associated Diagnosis") given the continuous independent variables of interest (child-related and family-related factors regarding age). For multinomial logistic regression analyses including two independent variables (one continuous independent variable and one categorical independent variable), an interaction term was included to account for any collinearity between independent variables on the dependent variable. **Table 1** includes a listing of all statistical analyses that were utilized to address these questions, and **Appendix 2** includes a coding manual with explicit definitions and outlined levels of all variables that were used for

descriptive, individual, and interactional analyses. Furthermore, to examine the predictive power of various child-related, family-related, and referring healthcare provider-related independent variables on the original dependent variable of interest ("Match of Referral and Associated Diagnosis"), the Generalized, Unbiased, Interaction Detection and Estimation (GUIDE; Loh & Zhou, 2020) machine learning algorithm was utilized to construct exploratory classification and regression trees and forests.

Table 1

Planned Analyses for Examining Sub-Questions for Primary Research Question #1

	Analysis Question:	Analysis Variables	Analysis Type
Child-Related Factors			
Individual Analyses:	Does presence of an ever comorbid ID diagnosis (current or previous) relate to matched referral for ASD and subsequent diagnosis of ASD?	Ever ID diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of a current comorbid global developmental delay diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Current global development delay diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of a previous comorbid global developmental delay diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Previous global development delay diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of a current comorbid speech-language impairment diagnosis	Current speech-language impairment diagnosis – Binary variable	Chi-square test of independence – with original dependent variable type only

	relate to matched referral for ASD and subsequent diagnosis of ASD?	Match of referral/diagnosis – Categorical variable	
	Does presence of a previous comorbid speech-language impairment diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Previous speech-language impairment diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of an ever comorbid genetic disorder diagnosis (current or previous) relate to matched referral for ASD and subsequent diagnosis of ASD?	Ever genetic disorder diagnosis –Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of another current comorbid diagnosis (not previously outlined) relate to matched referral for ASD and subsequent diagnosis of ASD?	Current other diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of another previous comorbid diagnosis (not previously outlined) relate to matched referral for ASD and subsequent diagnosis of ASD?	Previous other diagnosis - Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of a current ADHD diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Current ADHD diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types

	Does presence of previous ADHD diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Previous ADHD diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of a current anxiety/obsessive compulsive/adjustment disorder diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Anxiety/obsessive compulsive/adjustment disorder diagnosis – Binary variable Match of referral/ diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of a previous anxiety/obsessive compulsive/adjustment disorder diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Previous anxiety/obsessive compulsive/adjustment disorder diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does presence of an ever mood disorder diagnosis (current or previous) relate to matched referral for ASD and subsequent diagnosis of ASD?	Ever mood disorder diagnosis – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence– with original and alternative dependent variable types
	Does race/ethnicity of the child relate to matched referral for ASD and subsequent diagnosis of ASD?	Alternative race/ethnicity of child – Categorical variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does sex of the child relate to matched referral for ASD and subsequent diagnosis of ASD?	Biological sex of the child – Binary variable	Chi-square test of independence – with original and alternative

		Match of referral/diagnosis – Categorical variable	dependent variable types
	Does the binary primary language of the child relate to matched referral for ASD and subsequent diagnosis of ASD?	Binary primary language of the child – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does the child's age at time of clinic referral relate to matched referral for ASD and subsequent diagnosis of ASD?	Child's age at time of clinic referral – Continuous variable Match of referral/diagnosis – Categorical variable	Multinomial logistic regression – with original dependent variable type only
	Does the child's age at time of clinic diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Child's age at time of clinic diagnosis – Continuous variable Match of referral/diagnosis – Categorical variable	Multinomial logistic regression – with original dependent variable type only
Interaction Analyses:	Does the interaction of race/ethnicity and biological sex of the child relate to matched referral for ASD and subsequent diagnosis of ASD?	Re-code separate race/ethnicity and biological sex variables into new race/ethnicity by sex interaction variables – Categorical variable (see coding manual) Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does the interaction of race/ethnicity of the child and age at time of clinic referral relate to matched referral for ASD and subsequent diagnosis of ASD?	Alternative race/ethnicity of the child – Categorical variable Age at time of clinic referral - Continuous variable	Multinomial logistic regression with interaction term (2 independent variables; 1 dependent variable) – with original

		Match of referral/diagnosis – Categorical variable	dependent variable type only
	Does the interaction of race/ethnicity of the child and age at time of clinic diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Alternative race/ethnicity of the child – Categorical variable Age at time of clinic diagnosis – Continuous variable Match of referral/diagnosis – Categorical variable	Multinomial logistic regression with interaction term (2 independent variables; 1 dependent variable) – with original dependent variable type only
	Does the interaction of biological sex of the child and age at time of clinic referral relate to matched referral for ASD and subsequent diagnosis of ASD?	Biological sex of the child – Binary variable Age at time of clinic referral – Continuous variable Match of referral/diagnosis – Categorical variable	Multinomial logistic regression with interaction term (2 independent variables; 1 dependent variable) – with original dependent variable type only
	Does the interaction of biological sex of the child and age at time of clinic diagnosis relate to matched referral for ASD and subsequent diagnosis of ASD?	Biological sex of the child – Binary variable Age at time of clinic diagnosis – Continuous variable Match of referral/diagnosis – Categorical variable	Multinomial logistic regression with interaction term (2 independent variables; 1 dependent variable) – with original dependent variable type only
Family-Related Factors			
	Does caregiver-reported age of initial concern relate to matched referral for ASD and subsequent diagnosis of ASD?	Caregiver-reported age of initial concern – Continuous variable	Multinomial logistic regression – with original dependent variable type only

		Match of referral/diagnosis – Categorical variable	
	Does general caregiver-reported behavior of initial concern relate to matched referral for ASD and subsequent diagnosis of ASD?	General caregiver-reported behavior of initial concern – Categorical variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does household zip code relate to matched referral for ASD and subsequent diagnosis of ASD?	Household zip code – Categorical variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does family insurance type relate to matched referral for ASD and subsequent diagnosis of ASD?	Family insurance type – Binary variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original dependent variable type only
Referring Healthcare Provider-Related Factors			
	Does the practice type of the referring healthcare provider relate to matched referral for ASD and subsequent diagnosis of ASD?	Practice type of referring healthcare provider – Categorical variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types
	Does the clinical practice zip code of the referring healthcare provider relate to matched referral for ASD and subsequent diagnosis of ASD?	Clinical practice zip code of referring healthcare provider – Categorical variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types

	Does the professional role type of the referring healthcare provider relate to matched referral for ASD and subsequent diagnosis of ASD?	Professional role type of referring healthcare provider – Categorical variable Match of referral/diagnosis – Categorical variable	Chi-square test of independence – with original and alternative dependent variable types

In order to answer sub-questions associated with Research Question #2, a series of chi-square tests of independence and logistic regression analyses were conducted to determine which child-related, family-related, and referring healthcare provider-related factors (independent variables) were individually and interactionally associated with referral at or before children are three years of age (up to 47 months) versus after children are three years of age (48 months or older; dependent variable). For all chi-square tests of independence, two-way contingency tables were constructed to evaluate whether each of the categorical or binary independent variables (child-related, family-related, and referring healthcare provider-related factors) had a statistically significant effect on levels of the binary dependent variable (referral at or before three years of age, referral after three years of age). For situations in which the sample size of 2x2 contingency tables (binary independent variable, binary dependent variable) was not large enough to meet assumptions of the chi-square test of independence (at least five cases per chi-square contingency table cell), Fisher's exact test (Fisher, 1922) was alternatively utilized to calculate the significance of association between the two variables. Given that multiple tests were being conducted, statistical correction was again utilized to minimize the potential for false discovery rate. To do so, the Benjamini-Hochberg correction procedure (Benjamini & Hochberg, 1995) was applied to all individual chi-square analyses and Fisher's exact tests, and all individual

analyses and corrected analyses were directly compared and reported. Logistic regression analyses were used to predict the binary dependent variable (referral at or before three years of age, referral after three years of age) given the continuous independent variables of interest (family-related factors regarding age). For logistic regression analyses including two independent variables (one continuous independent variable and one categorical independent variable), an interaction term was included to account for interaction between independent variables on the dependent variable. **Table 2** includes a listing of all statistical analyses that were utilized to address these questions, and **Appendix 2** includes a coding manual with explicit definitions and outlined levels of all variables that were used for descriptive, individual, and interactional analyses. Additionally, to examine the predictive power of various child-related, family-related, and referring healthcare provider-related independent variables on the dependent variable of interest ("Timeliness of Referral to the Diagnostic Clinic"), the Generalized, Unbiased, Interaction Detection and Estimation (GUIDE; Loh & Zhou, 2020) machine learning algorithm was again utilized to construct exploratory classification and regression trees and forests.

Table 2

Planned Analyses for Examining Sub-Questions for Primary Research Question #2

	Analysis Question:	Analysis Variables	Analysis Type
Child-Related Factors			
Individual Analyses:	Does presence of a current ASD diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Current ASD diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence

	Does presence of a previous ASD diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Previous ASD diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does presence of an ever ID diagnosis (current or previous) relate to referral before/when children are three years of age vs. after three years of age?	Ever ID diagnosis – Binary variable Age at referral – Binary variable	Fisher's exact test
	Does presence of a current global developmental delay diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Current global development delay diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does presence of a previous global developmental delay diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Previous global development delay diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does presence of a current speech-language impairment diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Current speech-language impairment diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does presence of a previous speech-language impairment diagnosis relate to referral before/when	Previous speech-language impairment diagnosis – Binary variable	Chi-square test of independence

	children are three years of age vs. after children are three years of age?	Age at referral – Binary variable	
	Does presence of an ever genetic disorder/difference diagnosis (current or previous) relate to referral before/when children are three years of age vs. after children are three years of age?	Ever genetic disorder/difference diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does presence of another current diagnosis (not previously outlined) relate to referral before/when children are three years of age vs. after children are three years of age?	Current other diagnosis – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does presence of another previous diagnosis (not previously outlined) relate to referral before/when children are three years of age vs. after children are three years of age?	Previous other diagnosis – Binary variable Age at referral – Binary variable	Fisher's exact test
	Does presence of a current ADHD diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Current ADHD diagnosis – Binary variable Age at referral – Binary variable	Fisher's exact test
	Does presence of a previous ADHD diagnosis relate to referral before/when children are three	Previous ADHD diagnosis – Binary variable	Fisher's exact test

	years of age vs. after three years of age?	Age at referral – Binary variable	
	Does presence of a current anxiety/obsessive compulsive/ adjustment disorder diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Current anxiety/obsessive compulsive/adjustment disorder diagnosis – Binary variable Age at referral – Binary variable	Fisher's exact test
	Does presence of a previous anxiety/obsessive compulsive/adjustment disorder diagnosis relate to referral before/when children are three years of age vs. after three years of age?	Previous anxiety/obsessive compulsive/ adjustment/ disorder diagnosis – Binary variable Age at referral – Binary variable	Fisher's exact test
	Does presence of an ever mood disorder diagnosis (current or previous) relate to referral before/when children are three years of age vs. after three years of age?	Ever mood disorder diagnosis – Binary variable Age at referral – Binary variable	Fisher's exact test
	Does level of support required for those assigned a diagnosis of ASD relate to referral before/when children are three years of age vs. after three years of age?	ASD level of support required – Categorical variable Age at referral – Binary variable	Chi-square test of independence
	Does race/ethnicity of the child relate to referral before/when children are three years of age vs. after three years of age?	Alternative race/ethnicity of child – Categorical variable Age at referral – Binary variable	Chi-square test of independence

	Does biological sex of the child relate to referral before/when children are three years of age vs. after three years of age?	Biological sex of the child – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does general primary language of the child relate to referral before/when children are three years of age vs. after three years of age?	General primary language of the child – Categorical variable Age at referral – Binary variable	Chi-square test of independence
	Does binary primary language of the child relate to referral before/when children are three years of age vs. after three years of age?	Binary primary language of the child – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in early intervention (Birth to Three) services relate to referral before/when children are three years of age vs. after three years of age?	Early intervention enrollment – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in early childcare services relate to referral before/when children are three years of age vs. after three years of age?	Early childcare enrollment – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in Head Start/Early Head Start services relate to referral before/when children are three years of age vs. after three years of age?	Head Start/Early Head Start enrollment – Binary variable Age at referral – Binary variable	Chi-square test of independence

	Does reported enrollment in supplemental therapeutic services relate to referral before/when children are three years of age vs. after three years of age?	Supplemental therapeutic support enrollment – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in speech language therapy services relate to referral before/when children are three years of age vs. after three years of age?	Reported enrollment in speech-language therapy services – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in occupational therapy services relate to referral before/when children are three years of age vs. after three years of age?	Reported enrollment in occupational therapy services – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in physical therapy services relate to referral before/when children are three years of age vs. after three years of age?	Reported enrollment in physical therapy services – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported enrollment in psychological intervention services relate to referral before/when children are three years of age vs. after three years of age?	Reported enrollment in psychological intervention services – Binary variable Age at referral – Binary variable	Chi-square test of independence
	Does reported receipt of early special education/special	Early special education/special	Chi-square test of independence

	education services relate to referral before/when children are three years of age vs. after three years of age?	education receipt – Binary variable Age at referral – Binary variable	
Interaction Analyses:	Does the interaction of race/ethnicity and biological sex of the child relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate race/ethnicity and biological sex variables into new race/ethnicity by sex interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of comorbid presentation of ASD (ever) and ID (ever) relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and ID (ever) variables into new ASD (ever) by ID (ever) interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of comorbid presentation of ASD (ever) and GDD (ever) relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and GDD (ever) variables into new ASD (ever) by GDD (ever) interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of comorbid presentation of ASD (ever) and speech-language disorder (ever) relate	Re-code separate ASD (ever) and speech-language disorder (ever) variables into new ASD (ever) and	Chi-square test of independence

	to referral before/when children are three years of age vs. after three years of age?	speech-language disorder (ever) interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	
	Does the interaction of comorbid presentation of ASD (ever) and genetic difference/disorder (ever) relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and genetic disorder/difference (ever) variables into new ASD (ever) and genetic disorder/difference (ever) interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of comorbid presentation of ASD (ever) and ADHD (ever) relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and ADHD (ever) variables into new ASD (ever) and ADHD (ever) interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of comorbid presentation of ASD (ever) and anxiety/obsessive compulsive/adjustment disorder (ever) relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and anxiety/obsessive compulsive/adjustment disorder (ever) variables into new ASD (ever) and anxiety/obsessive compulsive/adjustment disorder (ever) interaction variables –	Chi-square test of independence

		Categorical variable (see coding manual) Age at referral – Binary variable	
	Does the interaction of comorbid presentation of ASD (ever) and mood disorder (ever) relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and mood disorder (ever) variables into new ASD (ever) and mood disorder (ever) interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and race/ethnicity of the child relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and race/ethnicity variables into new ASD (ever) and race/ethnicity interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and binary primary language of the child relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and binary primary language variables into new ASD (ever) and binary primary language interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and reported	Re-code separate ASD (ever) and early intervention	Chi-square test of independence

	enrollment in early intervention (Birth to Three) services relate to referral before/when children are three years of age vs. after three years of age?	enrollment variables into new ASD (ever) and early intervention enrollment interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in early childcare services relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and early childcare enrollment variables into new ASD (ever) and early childcare enrollment interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in Head Start/Early Head Start services relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and Head Start/Early Head Start enrollment variables into new ASD (ever) and Head Start/Early Head Start enrollment interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in supplemental therapeutic support services relate to referral before/when children are three	Re-code separate ASD (ever) and supplemental therapeutic support enrollment variables into new ASD (ever) and supplemental therapeutic support enrollment interaction	Chi-square test of independence

	years of age vs. after three years of age?	variables – Categorical variable (see coding manual) Age at referral – Binary variable	
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in speech-language therapy services relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and reported enrollment in speech-language therapy services variables into new ASD (ever) and enrollment in speech-language therapy services interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in occupational therapy services relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and reported enrollment in occupational therapy services variables into new ASD (ever) and enrollment in occupational therapy services interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in physical therapy services relate to referral before/when children are three	Re-code separate ASD (ever) and reported enrollment in physical therapy services variables into new ASD (ever) and enrollment in physical therapy services	Chi-square test of independence

	years of age vs. after three years of age?	interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	
	Does the interaction of diagnosis of ASD (ever) and reported enrollment in psychological intervention services relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and reported enrollment in psychological intervention services variables into new ASD (ever) and enrollment in psychological intervention services interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and reported receipt of early special education/special education services relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and receipt of early special education/special education variables into new ASD (ever) and receipt of early special education/special education interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
Family-Related Factors			
Individual Analyses:	Does caregiver-reported age of initial concern relate to referral before/when	Caregiver-reported age of initial concern – Continuous variable	Logistic regression (1 independent variable, 1 binary dependent variable)

	children are three years of age vs. after three years of age?	Age at referral – Binary variable	
	Does general caregiver-reported behavior of initial concern relate to referral before/when children are three years of age vs. after three years of age?	General caregiver-reported behavior of initial concern – Categorical variable Age at referral – Binary variable	Chi-square test of independence
	Does household zip code relate to referral before/when children are three years of age vs. after three years of age?	Household zip code – Categorical variable Age at referral – Binary variable	Chi-square test of independence
	Does family insurance type relate to referral before/when children are three years of age vs. after three years of age?	Family insurance type – Binary variable Age at referral – Binary variable	Chi-square test of independence
Interaction Analyses:	Does the interaction of diagnosis of ASD (ever) and caregiver-reported age of initial concern relate to referral before/when children are three years of age vs. after three years of age?	Ever diagnosis of ASD – Binary variable Caregiver-reported age of initial concern – Continuous variable Age at referral – Binary variable	Logistic regression with interaction term (2 independent variables; 1 binary dependent variable)
	Does the interaction of diagnosis of ASD (ever) and household zip code relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and household zip code variables into new ASD (ever) and household zip code interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence

	Does the interaction of diagnosis of ASD (ever) and family insurance type relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and family insurance type variables into new ASD (ever) and family insurance type interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
Referring Healthcare Provider-Related Factors			
Individual Analyses:	Does the practice type of the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	Practice type of referring healthcare provider – Categorical variable Age at referral – Binary variable	Chi-square test of independence
	Does the clinical practice zip code of the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	Clinical practice zip code of referring healthcare provider – Categorical variable Age at referral – Binary variable	Chi-square test of independence
	Does the professional role type of the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	Professional role type of referring healthcare provider – Categorical variable Age at referral – Binary variable	Chi-square test of independence
Interaction Analyses:	Does interaction of diagnosis of ASD (ever) and screening	Re-code separate ASD (ever) and screening measure type	Chi-square test of independence

	measure type administered by the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	administered by the referring healthcare provider variables into new ASD (ever) and screening measure type administered by the referring healthcare provider interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	
	Does the interaction of diagnosis of ASD (ever) and practice type of the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and practice type of referring healthcare provider variables into new ASD (ever) and practice type of referring healthcare provider interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence
	Does the interaction of diagnosis of ASD (ever) and clinical practice zip code of the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and clinical practice zip code of referring healthcare provider variables into new ASD (ever) and practice zip code of referring healthcare provider interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence

	Does the interaction of diagnosis of ASD (ever) and professional role type of the referring healthcare provider relate to referral before/when children are three years of age vs. after three years of age?	Re-code separate ASD (ever) and professional role type of referring healthcare provider variables into new ASD (ever) and professional role type of referring healthcare provider interaction variables – Categorical variable (see coding manual) Age at referral – Binary variable	Chi-square test of independence

Reliability Extraction and Coding of Data

Due to clinical protections surrounding patient medical data in the electronic health record, only personnel associated with the A&DD Clinic were allowed to access, extract, and code information from the HealthLink patient health records. Thus, to gather reliability information for the current study, a secondary graduate student researcher and doctoral psychology trainee from the A&DD Clinic was recruited to review extracted data. The secondary researcher was asked to review and code information for 20% of the extracted electronic health records. Then, following completion of the reliability check, the total percentage of interobserver agreement between the primary and secondary researchers was calculated, and any disagreements in coding between the primary and secondary researchers were resolved through verbal discussion and revision to the collected data (Cooper et al., 2020).

In total, the secondary researcher reviewed and coded 74 (20%) of 371 (entire sample) electronic health records across five separate days following the primary researcher's initial data collection period. Each individual record had 53 separate data items to review, which resulted in

a total of 3,922 different data items for the secondary researcher to check for reliability purposes. Across all records, a total of two disagreements occurred between the primary and secondary researchers. These disagreements were related to the "Assignment of Level of Support for ASD Diagnosis" variable (in which the primary researcher recorded the incorrect level of support for one electronic health record) and the "Current Assignment of Other Diagnosis – Anxiety/Obsessive Compulsive/Adjustment Disorder" variable (in which the primary researcher failed to record a current anxiety disorder diagnosis for one electronic health record). Both disagreements were resolved through verbal discussion and subsequently changed to fit with the secondary researcher's observations. Between researchers, the total interobserver agreement was 99.94%.

Chapter 3

Results

The purpose of this chapter is to present the results for the current research study. First, this chapter provides comprehensive information regarding the demographic characteristics of participants included in the study. Then, results from statistical analyses for the first and second primary research questions are presented and reviewed.

Descriptive Study Population Characteristics

Child-Related Factors

Table 3 presents diagnostic and referral characteristics of all 371 participants included in the current study. Of the entire sample, 236 individuals were provided with a diagnosis of ASD following service provision in the A&DD Clinic, and 28 individuals had received a diagnosis of ASD prior to participation in an A&DD diagnostic evaluation. 107 individuals had never received a diagnosis of ASD. Of the total individuals diagnosed with ASD, 63/236 currently diagnosed and 0/28 previously diagnosed were assigned a Level 1 ("requiring support") diagnostic qualifier, 64/236 currently diagnosed and 3/28 previously diagnosed a Level 2 ("requiring substantial support") qualifier, and 24/236 currently diagnosed and 2/28 previously diagnosed a Level 3 ("requiring very substantial support") qualifier. However, data regarding level of support was missing for 85/236 currently diagnosed and 23/28 previously diagnosed individuals. Of the children and adolescents who were diagnosed with ASD either prior to or following receipt of services in the A&DD Clinic, the following number of individuals were also diagnosed with co-occurring conditions: 12 with ID (8 currently diagnosed with ASD, 4 previously diagnosed with ASD); 39 with global developmental delay (33 currently diagnosed

with ASD, 6 previously diagnosed with ASD); 107 with a speech-language delay or disorder (97 currently diagnosed with ASD, 10 previously diagnosed with ASD); 28 with a genetic difference or disorder (23 currently diagnosed with ASD, 5 previously diagnosed with ASD); 44 with ADHD (32 currently diagnosed with ASD, 12 previously diagnosed with ASD); 40 with an anxiety, obsessive compulsive, or adjustment disorder (37 currently diagnosed with ASD, 3 previously diagnosed with ASD); and 10 with a mood disorder (10 currently diagnosed with ASD, 0 previously diagnosed with ASD). For individuals who completed a cognitive or developmental assessment as part of the diagnostic evaluation process, the average full scale cognitive score across all sample participants was 58 (n = 7; median = 57; range = 44-72; SD = 11.6), and the average full scale developmental quotient across participants was 64 (n = 20; median = 67.5; range = 20 – 85; SD = 16.0).

Of the entire sample, the majority of children and adolescents who received a diagnosis of ASD were matched for referral concerns related to the disorder (55.3%). However, 26.9% of individuals had a mismatched clinic referral. In these cases, some individuals were referred for other developmental concerns but received a subsequent diagnosis of ASD (8.6%), while others were referred for concerns related to ASD but did not receive a subsequent diagnosis of the disorder (18.3%). Finally, other children and adolescents were referred to the clinic for other developmental, social-emotional, or behavioral concerns, did not participate in a diagnostic evaluation for ASD, and did not receive a diagnosis of ASD (17.8%). Those who did not receive a subsequent diagnosis of ASD following a diagnostic evaluation in the clinic either received no new diagnosis at all (35.0%), received one new diagnosis (49.3%), or received two new diagnoses (15.7%).

Table 3
Child Diagnostic and Referral Characteristics

	n	% of sample
Diagnostic Classification		
Current ASD Diagnosis	236	63.6%
Previous ASD Diagnosis	28	7.5%
Ever ASD Diagnosis	264	71.1%
Level 1 Support	63	23.9%
Level 2 Support	67	25.4%
Level 3 Support	26	9.8%
Information Not Reported	108	40.9%
Current ID Diagnosis	13	3.5%
Previous ID Diagnosis	11	2.9%
Ever ID Diagnosis	24	6.47%
Mild Severity	10	41.6%
Moderate Severity	7	29.2%
Severe Severity	1	4.2%
Profound Severity	0	0.0%
Information Not Reported	6	25.0%
Ever ASD, Ever ID	12	3.23%
Current ASD, Current ID	5	
Current ASD, Previous ID	3	
Previous ASD, Current ID	2	
Previous ASD, Previous ID	2	
Current GDD Diagnosis	39	10.5%
Previous GDD Diagnosis	32	8.6%
Ever GDD Diagnosis	71	19.1%
Ever ASD, Ever GDD	39	10.5%
Current ASD, Current GDD	15	
Current ASD, Previous GDD	18	
Previous ASD, Current GDD	1	
Previous ASD, Previous GDD	5	
Current Speech-Language Diagnosis	119	32.1%
Previous Speech-Language Diagnosis	44	11.8%
Ever Speech-Language Diagnosis	163	43.9%
Ever ASD, Ever Speech-Language	107	28.8%
Current ASD, Current Speech-Language	74	
Current ASD, Previous Speech-Language	23	
Previous ASD, Current Speech-Language	5	
Previous ASD, Previous Speech-Language	5	

Current Genetic Diagnosis	5	1.4%
Previous Genetic Diagnosis	36	9.7%
Ever Genetic Diagnosis	41	11.1%
Ever ASD, Ever Genetic	28	7.5%
Current ASD, Current Genetic	1	
Current ASD, Previous Genetic	22	
Previous ASD, Current Genetic	4	
Previous ASD, Previous Genetic	1	
Current ADHD Diagnosis	18	4.9%
Previous ADHD Diagnosis	52	14.0%
Ever ADHD Diagnosis	70	18.9%
Ever ASD, Ever ADHD	44	11.9%
Current ASD, Current ADHD	3	
Current ASD, Previous ADHD	29	
Previous ASD, Current ADHD	5	
Previous ASD, Previous ADHD	7	
Current Anxiety/OCD/ Adjustment Diagnosis	25	6.8%
Previous Anxiety/OCD/ Adjustment Diagnosis	35	9.4%
Ever Anxiety/OCD/ Adjustment Diagnosis	60	16.2%
Ever ASD, Ever Anxiety/OCD/ Adjustment	40	10.8%
Current ASD, Current Anxiety/OCD/Adjustment	17	
Current ASD, Previous Anxiety/OCD/Adjustment	20	
Previous ASD, Current Anxiety/OCD/Adjustment	0	
Previous ASD, Previous Anxiety/OCD/Adjustment	3	
Current Mood Diagnosis	6	1.6%
Previous Mood Diagnosis	13	3.5%
Ever Mood Diagnosis	19	5.1%
Ever ASD, Ever Mood	10	2.7%
Current ASD, Current Mood	0	
Current ASD, Previous Mood	10	
Previous ASD, Current Mood	0	
Previous ASD, Previous Mood	0	
Match of Referral and Associated Diagnosis		
Referral for ASD, Subsequent Diagnosis of ASD	205	55.3%
Referral for Another Disorder, Subsequent Diagnosis of ASD	32	8.6%
Referral for ASD, No Subsequent Diagnosis of ASD	68	18.3%

Referral for Another Disorder, No Subsequent Diagnosis of ASD	66	17.8%
Alternative Match of Referral and Associated Diagnosis		
Match (Referral for ASD, Subsequent Diagnosis of ASD)	205	55.3%
Mismatched (Referral for Another Disorder, Subsequent Diagnosis of ASD; Referral for ASD, No Subsequent Diagnosis of ASD)	100	26.9%
Other (Referral for Another Disorder, No Subsequent Diagnosis of ASD)	66	17.8%
If No Subsequent Diagnosis of ASD		
No New Diagnosis	47	35.0%
ID Diagnosis	6	4.5%
GDD Diagnosis	12	8.9%
Speech-Language Diagnosis	24	18.0%
Genetic Diagnosis	4	3.0%
ADHD Diagnosis	11	8.2 %
Anxiety/OCD/Adjustment Diagnosis	6	4.5%
Mood Diagnosis	3	2.2%
ID and Speech-Language Diagnoses	2	1.5%
ADHD and Speech-Language Diagnoses	2	1.5%
ADHD and GDD Diagnoses	2	1.5%
GDD and Speech-Language Diagnoses	10	7.5%
Mood and Speech-Language Diagnoses	3	2.2%
Anxiety/OCD/Adjustment and Speech-Language Diagnoses	2	1.5%

Table 4 presents demographic characteristics of all child and adolescent participants from the study. The majority of individuals from the sample population were White/Caucasian and Non-Hispanic/Latino (67.6%), male (71.7%), and spoke English as their primary language (93.5%). Similarly, of the individuals who received a diagnosis of ASD prior to or following completion of a diagnostic evaluation in the A&DD Clinic, the majority also shared the same demographic characteristics as the total sample. Of those who were currently diagnosed with ASD, 71.6% were White/Caucasian and Non-Hispanic/Latino, 76.7% were male, and 93.6% spoke English. For those who were previously diagnosed with ASD, 70.4% were White/Caucasian and Non-Hispanic/Latino, 71.4% were male, and 92.9% spoke English as their

primary language. Information regarding race/ethnicity was not reported in the electronic health record for ten total participants.

Table 4
Child Demographic Characteristics

	n	% of sample
Specific Race/Ethnicity of Child		
White/Caucasian, Non-Hispanic/Latino	251	67.7%
White/Caucasian, Hispanic/Latino	41	11.1%
Black/African American, Non-Hispanic/Latino	41	11.1%
Black/African American, Hispanic/Latino	0	0.0%
Asian/Asian American, Non-Hispanic/Latino	21	5.6%
Asian/Asian American, Hispanic/Latino	2	0.5%
American Indian/Alaska Native, Non-Hispanic/Latino	2	0.5%
American Indian/Alaska Native, Hispanic/Latino	0	0.0%
Native Hawaiian/Other Islander, Non-Hispanic/Latino	1	0.3%
Native Hawaiian/Other Islander, Hispanic/Latino	2	0.5%
Information Not Reported	10	2.7%
Alternative Race/Ethnicity of Child		
White/Caucasian, Non-Hispanic/Latino	251	67.7%
White/Caucasian, Hispanic/Latino	41	11.1%
Black/African American, Non-Hispanic/Latino	41	11.1%
Asian/Asian American, Non-Hispanic/Latino	21	5.6%
Other Race/Ethnicity	7	1.8%
Information Not Reported	10	2.7%
Biological Sex of Child		
Male	266	71.7%
Male, Yes ASD	201	75.6%
Current ASD	181	
Previous ASD	20	
Female	105	28.3%
Female, Yes ASD	63	60.0%
Current ASD	55	
Previous ASD	8	
Specific Race/Ethnicity and Sex of Child		
White/Caucasian, Non-Hispanic/Latino, Male	181	48.8%
White/Caucasian, Non-Hispanic/Latino, Female	70	18.9%
White/Caucasian, Hispanic/Latino, Male	25	6.8%
White/Caucasian, Hispanic/Latino, Female	16	4.3%
Black/African American, Non-Hispanic/Latino, Male	30	8.1%

Black/African American, Non-Hispanic/Latino, Female	11	3.0%
Black/African American, Hispanic/Latino, Male	0	0.0%
Black/African American, Hispanic/Latino, Female	0	0.0%
Asian/Asian American, Non-Hispanic/Latino, Male	13	3.5%
Asian/Asian American, Non-Hispanic/Latino, Female	8	2.1%
Asian/Asian American, Hispanic/Latino, Male	2	0.5%
Asian/Asian American, Hispanic/Latino, Female	0	0.0%
American Indian/Alaska Native, Non-Hispanic/Latino, Male	2	0.5%
American Indian/Alaska Native, Non-Hispanic/Latino, Female	0	0.0%
American Indian/Alaska Native, Hispanic/Latino, Male	0	0.0%
American Indian/Alaska Native, Hispanic/Latino, Female	0	0.0%
Native Hawaiian/Other Islander, Non-Hispanic/Latino, Male	1	0.3%
Native Hawaiian/Other Islander, Non-Hispanic/Latino, Female	0	0.0%
Native Hawaiian/Other Islander, Hispanic/Latino, Male	2	0.5%
Native Hawaiian/Other Islander, Hispanic/Latino, Female	0	0.0%
Information Not Reported	10	2.7%
General Race/Ethnicity and Sex of Child		
White/Caucasian, Non-Hispanic/Latino, Male	181	48.8%
White/Caucasian, Non-Hispanic/Latino, Female	70	18.9%
White/Caucasian, Hispanic/Latino, Male	25	6.8%
White/Caucasian, Hispanic/Latino, Female	16	4.3%
Non-White/Caucasian, Non-Hispanic/Latino, Male	46	12.3%
Non-White/Caucasian, Non-Hispanic/Latino, Female	19	5.1%
Non-White/Caucasian, Hispanic/Latino, Male	4	1.1%
Non-White/Caucasian, Hispanic/Latino, Female	0	0.0%
Information Not Reported	10	2.7%
Ever ASD, Specific Race/Ethnicity		
White/Caucasian, Non-Hispanic/Latino, No ASD	68	18.3%
White/Caucasian, Non-Hispanic/Latino, Yes ASD	183	49.3%
Current ASD	164	
Previous ASD	19	
White/Caucasian, Hispanic/Latino, No ASD	19	5.1%
White/Caucasian, Hispanic/Latino, Yes ASD	22	6.0%
Current ASD	19	
Previous ASD	3	
Black/African American, Non-Hispanic/Latino, No ASD	11	3.0%
Black/African American, Non-Hispanic/Latino, Yes ASD	30	8.2%
Current ASD	29	

Previous ASD	1	
Black/African American, Hispanic/Latino, No ASD	0	0.0%
Black/African American, Hispanic/Latino, Yes ASD	0	0.0%
Current ASD	0	
Previous ASD	0	
Asian/Asian American, Non-Hispanic/Latino, No ASD	5	1.4%
Asian/Asian American, Non-Hispanic/Latino, Yes ASD	16	4.3%
Current ASD	13	
Previous ASD	3	
Asian/Asian American, Hispanic/Latino, No ASD	1	0.2%
Asian/Asian American, Hispanic/Latino, Yes ASD	1	0.2%
Current ASD	1	
Previous ASD	0	
American Indian/Alaska Native, Non-Hispanic/Latino, No ASD	0	0.0%
American Indian/Alaska Native, Non-Hispanic/Latino, Yes ASD	2	0.7%
Current ASD	1	
Previous ASD	1	
American Indian/Alaska Native, Hispanic/Latino, No ASD	0	0.0%
American Indian/Alaska Native, Hispanic/Latino, Yes ASD	0	0.0%
Current ASD	0	
Previous ASD	0	
Native Hawaiian/Other Islander, Non-Hispanic/Latino, No ASD	0	0.0%
Native Hawaiian/Other Islander, Non-Hispanic/Latino, Yes ASD	1	0.2%
Current ASD	1	
Previous ASD	0	
Native Hawaiian/Other Islander, Hispanic/Latino, No ASD	1	0.2%
Native Hawaiian/Other Islander, Hispanic/Latino, Yes ASD	1	0.2%
Current ASD	1	
Previous ASD	0	
Information Not Reported	10	2.7%
Ever ASD, General Race/Ethnicity		
White/Caucasian, Non-Hispanic/Latino, No ASD	68	18.3%
White/Caucasian, Non-Hispanic/Latino, Yes ASD	183	49.3%
Current ASD	164	
Previous ASD	19	

White/Caucasian, Hispanic/Latino, No ASD	19	5.1%
White/Caucasian, Hispanic/Latino, Yes ASD	22	6.0%
Current ASD	19	
Previous ASD	3	
Non-White/Caucasian, Non-Hispanic/Latino, No ASD	16	4.3%
Non-White/Caucasian, Non-Hispanic/Latino, Yes ASD	49	13.3%
Current ASD	44	
Previous ASD	5	
Non-White/Caucasian, Hispanic/Latino, No ASD	2	0.5%
Non-White/Caucasian, Hispanic/Latino, Yes ASD	2	0.5%
Current ASD	2	
Previous ASD	0	
Information Not Reported	10	2.7%
Specific Primary Language		
English	347	93.5%
Spanish	17	4.6%
American Sign Language	1	0.3%
Mandarin	1	0.3%
Albanian	1	0.3%
Arabic	2	0.5%
Cambodian	2	0.5%
Binary Primary Language		
English	347	93.5%
Other	24	6.5%
Ever ASD, Binary Primary Language		
English, No ASD	100	27.0%
English, Yes ASD	247	66.6%
Current ASD	221	
Previous ASD	26	
Other, No ASD	7	1.8%
Other, Yes ASD	17	4.6%
Current ASD	15	
Previous ASD	2	

Table 5 presents information regarding the chronological age at which children and adolescents were at various points in the A&DD Clinic's service provision process. All ages are reported in months. Across the entire sample, the majority of participants were at or younger than the age of three when their family was referred to the clinic (51.2%), but the average age of

referral was 60.8 months. Once referred to the A&DD Clinic, families waited an average of 4.2 months before being contacted for scheduling purposes, an additional 3.8 months to be seen for an initial intake interview session, another 2 months to finish the diagnostic assessment process, and an additional 15-16 days to receive assessment feedback and potential new diagnoses. For the entire sample, the delay between age at clinic referral and age at feedback/diagnosis was 10.6 months. However, for children and adolescents who received a subsequent diagnosis of ASD following the diagnostic evaluation process in the A&DD Clinic, variations in this trajectory were observed. For individuals who received a new diagnosis of ASD, the average age of referral to the A&DD Clinic was 58.7 months. Once referred to the clinic, families again waited an average of 4.2 months to be contacted for scheduling, another 3.4 months to be seen for an intake interview, an additional 1.8 months to complete the assessment process, and another 15-16 days to receive the ASD diagnosis. While the delay between age at clinic referral and diagnosis was slightly shorter for children who received a new diagnosis of ASD than for those of the total study sample (10 months, as opposed to 10.6 months), children who received a subsequent diagnosis of ASD were referred and diagnosed earlier than their alternative diagnostic counterparts (58.7 months at time of referral instead of 60.8 months; 68.7 months at time of feedback/diagnosis instead of 71.4 months).

Table 5

Child Chronological Age at A&DD Contact Points in Service Provision Process

	Mean	Median	Range	SD
Age at Clinic Referral				
Total Sample Reviewed	60.8	45.0	14-216	44.6
ASD Diagnosis in A&DD	58.7	43.5	14-213	42.7
Age at Initial Clinic Contact				
Total Sample Reviewed	65.0	50.0	14-217	45.3
ASD Diagnosis in A&DD	62.9	48.0	15-213	43.5

Age at Intake Interview Session				
Total Sample Reviewed	68.8	55.0	14-219	45.5
ASD Diagnosis in A&DD	66.3	51.0	16-216	43.5
Age at Diagnostic Assessment Session				
Total Sample Reviewed	70.8	57.0	18-223	45.5
ASD Diagnosis in A&DD	68.1	52.5	21-218	43.2
Age at Feedback Session				
Total Sample Reviewed	71.4	57.0	18-227	45.6
ASD Diagnosis in A&DD	68.7	53.0	21-218	43.2

Information regarding the types of therapeutic services and special education supports that children and adolescents received are presented in **Table 6**. Of the entire sample, the majority of individuals were enrolled in early intervention (Birth to Three) services (51.7%) and some type of community-based therapeutic support services (74.1%) prior to participation in the A&DD diagnostic evaluation process. Speech-language therapy was the most common outpatient support that children and adolescents accessed (52.0%). Additionally, about half of the total sample (50.1%) qualified for and received either special education or early special education supports within the public school system, with many individuals receiving either speech-language therapy (39.9%) or occupational therapy (28.8%) in the educational setting. Of individuals who received a diagnosis of ASD prior to or following completion of a diagnostic evaluation in the A&DD Clinic, a large percentage accessed early intervention supports (36.4% total; 122 currently diagnosed with ASD, 13 previously diagnosed with ASD) and some type of therapeutic support services within the community (52.8% total; 173 currently diagnosed with ASD, 23 previously diagnosed with ASD). Speech-language therapy was again the most commonly accessed support (36.1% total; 120 currently diagnosed with ASD, 14 previously diagnosed with ASD), but many individuals with ASD also participated in occupational therapy

(25.1% total; 83 currently diagnosed with ASD, 10 previously diagnosed with ASD) and psychological intervention (17.5% total; 48 currently diagnosed with ASD, 17 previously diagnosed with ASD) services. Further, over one third of individuals medically diagnosed with ASD (35.0% total; 110 currently diagnosed with ASD, 20 previously diagnosed with ASD) received special education or early special education services.

Table 6
Reported Access to Therapeutic and Special Education Services

	n	% of sample
Early Intervention Programming		
Total Sample Reviewed	192	51.7%
Ever ASD Diagnosis	135	36.4%
Current ASD	122	
Previous ASD	13	
Early Childcare Services		
Total Sample Reviewed	56	15.1%
Ever ASD Diagnosis	37	9.9%
Current ASD	34	
Previous ASD	3	
Head Start/Early Head Start Programming		
Total Sample Reviewed	21	5.7%
Ever ASD Diagnosis	13	3.5%
Current ASD	13	
Previous ASD	0	
Any Therapeutic Support Services		
Total Sample Reviewed	275	74.1%
Ever ASD Diagnosis	196	52.8%
Current ASD	173	
Previous ASD	23	
Speech-Language Therapy Services		
Total Sample Reviewed	193	52.0%
Ever ASD Diagnosis	134	36.1%
Current ASD	120	
Previous ASD	14	
Occupational Therapy Services		

Total Sample Reviewed	126	34.0%
Ever ASD Diagnosis	93	25.1%
Current ASD	83	
Previous ASD	10	
Physical Therapy Services		
Total Sample Reviewed	61	16.4%
Ever ASD Diagnosis	37	9.9%
Current ASD	33	
Previous ASD	4	
Psychological Intervention Services		
Total Sample Reviewed	88	23.7%
Ever ASD Diagnosis	65	17.5%
Current ASD	48	
Previous ASD	17	
Special Education/Early Special Education Services		
Total Sample Reviewed	186	50.1%
Ever ASD Diagnosis	130	35.0%
Current ASD	110	
Previous ASD	20	
Total Sample IDEA Disability Classification		
Autism Spectrum Disorder	35	18.8%
Intellectual Disability	3	1.6%
Specific Learning Disability	2	1.1%
Other Health Impairment	14	7.5%
Emotional Behavioral Disability	5	2.8%
Speech/Language Impairment	17	9.1%
Deafness	1	0.5%
Hearing Impairment	2	1.1%
Significant Developmental Delay	26	14.0%
Classification Not Reported	81	43.5%
School-Based Speech-Language Therapy		
Total Sample	148	39.9%
School-Based Occupational Therapy		
Total Sample	107	28.8%
School-Based Physical Therapy		
Total Sample	43	11.6%

School-Based Psychological Intervention		
Total Sample	30	8.1%

Family-Related Factors

In addition to demographic characteristics describing the children and adolescents who were seen in the A&DD Clinic, family-related demographic data was also collected. **Table 7** presents information regarding the chronological age at which caregivers initially became concerned about their child's development and what the initial behavior of concern was. Again, all ages are reported in months. Across the total sample, the average age of initial concern was 21.4 months. For caregivers of children who were diagnosed with ASD while visiting the A&DD Clinic, the average age of initial concern was 19.0 months, suggesting that these families had concerns about their child's development over two months earlier than caregivers of children with other diagnostic profiles. However, this information was unavailable for 214 of the 371 total electronic health records.

Across the entire sample, families most frequently reported specific initial concerns regarding delays or differences in speech and language skills (23.0%), delays or differences across global development (4.6%), challenging behaviors (4.3%), language regression (3.5%), or more than one initial concern (3.7%). When behavioral concerns were grouped into broader general categories, commonly indicated concerns included delays, differences, or regression in speech and language skills (26.5%) and motor or global developmental skills (7.9%), as well as social communication differences (5.6%). Of individuals who received a diagnosis of ASD prior to or following completion of the diagnostic evaluation process in A&DD, the most commonly-reported behaviors of concern also fell into these three general categories (53.4% currently diagnosed with ASD and 69.2% previously diagnosed with ASD reporting concerns related to

speech and language skills; 16.1% currently diagnosed and 15.4% previously diagnosed reporting concerns with motor or global developmental skills; 12.7% currently diagnosed and 7.7% previously diagnosed reporting concerns with social communication). However, due to a lack of information in the electronic health record, data regarding initial behavior of concern was unavailable for 180 individuals from the total sample.

Table 7

Caregiver-Reported Age and Behavior of Initial Concern

	Mean	Median	Range	SD
Chronological Age of Initial Concern				
Total Sample Reviewed	21.4	18.0	0-96	14.2
ASD Diagnosis in A&DD	19.0	18.0	0-60	11.5

	n	% of sample
Specific Behavior of Initial Concern		
Delays or Differences in Speech/Language Skills	85	23.0%
Language Regression	13	3.5%
Delays or Differences in Motor Skills	8	2.2%
Delays or Differences Across Global Development	17	4.6%
Global Developmental Regression	4	1.1%
Odd Social Communication Skills	5	1.3%
Lack of Social Interaction	9	2.4%
Lack of Eye Contact	7	1.9%
Restrictive and Repetitive Behaviors	9	2.4%
Challenging Behaviors	16	4.3%
Medical Complications	4	1.1%
More Than One Initial Concern	14	3.7%
Information Not Reported	180	48.5%
Grouped General Behavior of Initial Concern		
Delays, Differences, or Regression in Speech/ Language Skills	98	26.5%
Delays, Differences, or Regression in Motor or Global Developmental Skills	29	7.9%
Social Communication Differences	21	5.6%
Restrictive and Repetitive Behaviors	9	2.4%
Challenging Behaviors	16	4.3%
Medical Complications	4	1.1%
More Than One Initial Concern	14	3.7%
Information Not Reported	180	48.5%

Ever ASD, General Behavior of Initial Concern		
Delays, Differences, or Regression in Speech/ Language Skills, No ASD	26	7.1%
Delays, Differences, or Regression in Speech/ Language Skills, Yes ASD	72	19.4%
Current ASD	63	
Previous ASD	9	
Delays, Differences, or Regression in Motor or Global Developmental Skills, No ASD	11	3.0%
Delays, Differences, or Regression in Motor or Global Developmental Skills, Yes ASD	18	4.9%
Current ASD	16	
Previous ASD	2	
Social Communication Differences, No ASD	5	1.3%
Social Communication Differences, Yes ASD	16	4.3%
Current ASD	15	
Previous ASD	1	
Restrictive and Repetitive Behaviors, No ASD	2	0.5%
Restrictive and Repetitive Behaviors, Yes ASD	7	1.9%
Current ASD	7	
Previous ASD	0	
Challenging Behaviors, No ASD	10	2.7%
Challenging Behaviors, Yes ASD	6	1.6%
Current ASD	6	
Previous ASD	0	
Medical Complications, No ASD	1	0.3%
Medical Complications, Yes ASD	3	0.8%
Current ASD	3	
Previous ASD	0	
More Than One Initial Concern, No ASD	5	1.3%
More Than One Initial Concern, Yes ASD	9	2.4%
Current ASD	8	
Previous ASD	1	
Information Not Reported	180	48.5%

Table 8 presents additional demographic characteristics of families whose children and adolescents were included in the current study. From the total sample, the majority of families had private health insurance (59.6%) and most commonly lived in geographic locations within metro (56.1%), rural (15.1%), or urban (14.3%) health service areas in the state of Wisconsin. Families of children who received a diagnosis of ASD during the A&DD evaluation process had

similar demographic characteristics regarding insurance type (61.2% with private insurance), while the majority of families of children who had previously received a diagnosis of ASD had public health insurance (57.1%). Regardless of having received a diagnosis of ASD before or during the A&DD diagnostic evaluation, families of these children had similar characteristics to the larger sample regarding geographic location (53.4% currently diagnosed and 62.1% previously diagnosed living in metro locations; 14.4% currently diagnosed and 13.8% previously diagnosed living in rural locations; 15.3% currently diagnosed and 20.7% previously diagnosed living in urban locations).

Table 8
Family Demographic Characteristics

	n	% of sample
Health Insurance Type		
Public Insurance	150	40.4%
Private Insurance	221	59.6%
Ever ASD, Health Insurance Type		
Public Insurance, No ASD	42	11.3%
Public Insurance, Yes ASD	108	29.1%
Current ASD	92	
Previous ASD	16	
Private Insurance, No ASD	64	17.3%
Private Insurance, Yes ASD	157	42.3%
Current ASD	145	
Previous ASD	12	
Household Zip Code Area		
Metro Service Area	208	56.1%
Urban Service Area	53	14.3%
Mixed Service Area	35	9.4%
Rural Service Area	56	15.1%
Out of State Area	19	5.1%
Ever ASD, Household Zip Code		
Metro Service Area, No ASD	64	17.3%
Metro Service Area, Yes ASD	144	38.8%
Current ASD	126	

Previous ASD	18	
Urban Service Area, No ASD	11	3.0%
Urban Service Area, Yes ASD	42	11.3%
Current ASD	36	
Previous ASD	6	
Mixed Service Area, No ASD	6	1.6%
Mixed Service Area, Yes ASD	29	7.8%
Current ASD	29	
Previous ASD	0	
Rural Service Area, No ASD	18	4.9%
Rural Service Area, Yes ASD	38	10.2%
Current ASD	34	
Previous ASD	4	
Out of State Area, No ASD	7	1.9%
Out of State Area, Yes ASD	12	3.2%
Current ASD	11	
Previous ASD	1	

Referring Healthcare Provider-Related Factors

In addition to child and family demographics, information regarding the characteristics of referring healthcare providers was also reviewed. **Table 9** presents data related to practice features and professional qualifications of referring healthcare providers for children and adolescents included in the current study. In total, only 7.8% of referring providers mentioned having completed developmental and/or disorder-specific screening for ASD in the electronic health record. Of those individuals who reported use of screening practices, the ASQ-3 was the most commonly reported developmental screening tool, and the M-CHAT-R/F was the most widely reported disorder-specific screening tool for ASD. However, this information was not included or available for 342 individuals, thus making it unclear as to whether screening was not conducted by the healthcare providers or not reported on the clinic referral form. Across the entire sample, children and adolescents most frequently had a referring healthcare provider who worked in a pediatric primary care setting (57.7%), was located in a metro health service area in

the state of Wisconsin (69.8%), and was licensed as an MD (81.9%). Similarly, of the individuals who received a diagnosis of ASD before or following completion of a diagnostic evaluation in the A&DD Clinic, the majority also had referring healthcare providers who shared similar demographic characteristics with the total sample. Of those children and adolescents who were currently diagnosed with ASD, 60.9% had a referring healthcare provider who worked in a pediatric primary care location, 66.9% who was located in a metro health service area, and 83.1% who was licensed as an MD. For those who were previously diagnosed with ASD, 53.3% had a referring provider who worked in pediatric primary care, 78.6% who was located in a metro service area, and 85.7% who was licensed as an MD provider.

Table 9
Referring Healthcare Provider Practice Features and Professional Qualifications

	n	% of sample
Reported Screening Measure Type		
Developmental Screening	2	0.5%
ASD Disorder-Specific Screening	19	5.1%
Developmental and Disorder-Specific Screening	8	2.2%
No Screening Reported	342	92.2%
If Developmental Screening – Tool Name		
ASQ-3	5	50.0%
DAYC-2	1	10.0%
Not Reported	4	40.0%
If ASD Disorder-Specific Screening – Tool Name		
M-CHAT-R/F	17	65.4%
Not Reported	11	34.6%
Practice Type		
Pediatric Primary Care	214	57.7%
Family Medicine Primary Care	113	30.5%
Pediatric Specialty Care	44	11.8%
Ever ASD, Practice Type		
Pediatric Primary Care, No ASD	55	14.8%
Pediatric Primary Care, Yes ASD	159	42.9%

Current ASD	143	
Previous ASD	16	
Family Medicine Primary Care, No ASD	37	10.0%
Family Medicine Primary Care, Yes ASD	76	20.5%
Current ASD	72	
Previous ASD	4	
Pediatric Specialty Care, No ASD	14	3.7%
Pediatric Specialty Care, Yes ASD	30	8.1%
Current ASD	20	
Previous ASD	10	
Clinical Practice Zip Code Area		
Metro Service Area	259	69.8%
Urban Service Area	33	8.9%
Mixed Service Area	26	7.1%
Rural Service Area	38	10.2%
Out of State Service Area	15	4.0%
Ever ASD, Clinical Practice Zip Code		
Metro Service Area, No ASD	79	21.3%
Metro Service Area, Yes ASD	180	48.5%
Current ASD	158	
Previous ASD	22	
Urban Service Area, No ASD	7	1.9%
Urban Service Area, Yes ASD	26	7.0%
Current ASD	23	
Previous ASD	3	
Mixed Service Area, No ASD	4	1.1%
Mixed Service Area, Yes ASD	22	6.0%
Current ASD	21	
Previous ASD	1	
Rural Service Area, No ASD	11	2.9%
Rural Service Area, Yes ASD	27	7.3%
Current ASD	25	
Previous ASD	2	
Out of State Service Area, No ASD	6	1.6%
Out of State Service Area, Yes ASD	9	2.4%
Current ASD	9	
Previous ASD	0	
Provider Role Type		
MD Provider	304	81.9%
DO Provider	25	6.7%
NP Provider	27	7.3%

PA Provider	15	4.1%
Ever ASD, Provider Role Type		
MD Provider, No ASD	84	22.6%
MD Provider, Yes ASD	220	59.3%
Current ASD	196	
Previous ASD	24	
DO Provider, No ASD	8	2.1%
DO Provider, Yes ASD	17	4.6%
Current ASD	15	
Previous ASD	2	
NP Provider, No ASD	9	2.4%
NP Provider, Yes ASD	18	4.9%
Current ASD	16	
Previous ASD	2	
PA Provider, No ASD	6	1.7%
PA Provider, Yes ASD	9	2.4%
Current ASD	9	
Previous ASD	0	

Statistical Analyses – Research Question #1

In order to examine which child-related, family-related, and referring healthcare provider-related factors (independent variables) were associated with match of referral and subsequent diagnosis (dependent variable), a variety of chi-square tests of independence and multinomial logistic regression analyses were conducted. As outlined in the methods, an alternative version of the dependent variable ("Alternative Match of Referral and Associated Diagnosis") was supplementally utilized in situations where the sample size was not large enough to include two of the four separate levels of the original dependent variable ("Match of Referral and Associated Diagnosis") and the two levels needed to be collapsed into one new level. The Benjamini-Hochberg correction procedure was applied to all individual chi-square analyses to control for false discovery rate, and the GUIDE machine learning algorithm was utilized to examine additional relationships between variables.

Chi-Square Tests of Independence

A total of 23 chi-square analyses were run with the original version (four separate levels) of the dependent variable, and 20 additional analyses were completed with the alternative dependent variable version (three separate levels) when cell sample sizes were insufficient for the "referral for another disorder and subsequent diagnosis of ASD" and "referral for ASD and no subsequent diagnosis of ASD" levels. Altogether, 43 chi-square analyses were conducted to examine the relationships of interest. Across both dependent variable types, 32 of these analyses examined associations with child-related factors, five with family-related factors, and six with referring healthcare provider-related factors.

Child-Related Factors. Of the chi-square tests of independence that were conducted with the original version of the dependent variable, a total of seven emerged as statistically significant. Having a previous or current diagnosis of ID (X^2 =11.7, p = 0.01), a current diagnosis of global developmental delay (X^2 = 12.6, p = 0.01), a current non-developmental or non-genetic diagnosis (X^2 = 16.7, p < 0.00), a current diagnosis of ADHD (X^2 = 18.6, p < 0.00), or a previous or current diagnosis of a mood disorder (X^2 = 8.4, p = 0.04) all appeared to be associated with match of referral and associated diagnosis. Biological sex of the child (X^2 = 8.7, p = 0.03) and the interaction of biological sex and race/ethnicity of the child (X^2 = 33.5, p = 0.01) emerged as associated factors as well. All seven tests maintained statistical significance upon application of the Benjamini-Hochberg correction procedure (with a correction level of 0.25), and three additional tests (having a previous or current diagnosis of a genetic disorder or difference; having a previous global developmental delay diagnosis; having a previous diagnosis of a non-developmental or non-genetic disorder) emerged as newly significant but weaker in

their association with match of referral and diagnosis. However, of these tests, all but one variable (biological sex of the child) had at least one underfilled cell within the chi-square contingency table, which prompted the researcher to evaluate additional relationships between the independent variables of interest and the alternative version of the dependent variable.

When levels of the dependent variable were collapsed and the alternative dependent variable version was utilized, four of the original six underfilled chi-square analyses continued to be significant, and significance for one additional test emerged. When cell numbers of the contingency table were more fully filled, a previous or current diagnosis of ID ($X^2 = 7.9$, $p = 0.02$), a current diagnosis of global developmental delay ($X^2 = 10.9$, $p < 0.00$), a current diagnosis of ADHD ($X^2 = 13.7$, $p < 0.00$), and the interaction of biological sex and race/ethnicity ($X^2 = 25.9$, $p = 0.01$) all continued to be associated with match of referral and associated diagnosis. Additionally, having a previous or current diagnosis of a genetic disorder or difference ($X^2 = 6.8$, $p = 0.03$) also emerged as an important factor in predicting match of referral and diagnosis. Upon application of the Benjamini-Hochberg correction, all five tests maintained statistical significance, and three additional tests (having a previous global developmental delay diagnosis; having a current non-developmental or non-genetic diagnosis; having a previous or current diagnosis of a mood disorder) emerged as newly significant but less strong in their relation to match of referral and associated diagnosis. However, of these significant chi-square analyses, it is important to note that three continued to have contingency tables with at least one underfilled cell, suggesting that some level of caution should be applied when interpreting these analyses. **Table 10** includes a listing of all chi-square tests of independence that were completed for the various child-related factors of interest.

In order to look more carefully at where potential cell-level variations emerged for the statistically significant chi-square tests of independence, cell by cell comparisons were conducted to examine differences between expected and observed frequencies. This level of visual analysis was reserved for only the strongest (based on p-value) and most sound (based on sufficient contingency table cell numbers) relationships, which included four chi-square analyses with child-related variables. **Appendix 3** includes individual contingency tables with observed and expected frequencies for each analysis of interest.

Upon visual analysis of the biological sex contingency table, it appeared that of the individuals who were referred for and diagnosed with ASD, more of them were males than expected and fewer were females than expected. Based on review of the contingency table that examined ever having an ID, it emerged that of the individuals who were referred for and subsequently diagnosed with ASD, fewer than expected had received a previous or current diagnosis of ID. For the contingency table that presented having a current global developmental delay diagnosis, it appeared that of the children who received a diagnosis following the evaluation process, fewer were referred and diagnosed with ASD than expected. Inversely, of the children who did not receive a current diagnosis of global developmental delay, more were referred for and diagnosed with ASD than expected. Finally, after visual analysis of the ever genetic disorder contingency table, it emerged that of the individuals who were referred for ASD and not diagnosed with ASD, fewer than expected had either a previous or current diagnosis of a genetic disorder or difference. Additionally, of those who were referred for another disorder and were not subsequently diagnosed with ASD, more had received a genetic diagnosis at some point in time than expected.

Table 10

Chi-Square Tests of Independence – Child-Related Factors

	Chi-Square Test of Independence		
	X^2	p-value	DF
Use of Original Dependent Variable			
Individual Analyses:			
Ever ID Diagnosis	11.7	0.01*°′	3
Current GDD Diagnosis	12.6	0.01*°′	3
Previous GDD Diagnosis	5.6	0.13°′	3
Current SL Diagnosis	3.3	0.35	3
Previous SL Diagnosis	4.1	0.25	3
Ever Genetic Diagnosis	6.9	0.08°′	3
Current Other Diagnosis	16.7	< 0.00*°′	3
Previous Other Diagnosis	6.7	0.08°′	3
Current ADHD Diagnosis	18.6	< 0.00*°′	3
Previous ADHD Diagnosis	2.4	0.49	3
Current Anx/OCD/Adj Diagnosis	3.6	0.30	3
Previous Anx/OCD/Adj Diagnosis	2.9	0.40	3
Ever Mood Diagnosis	8.4	0.04*°′	3
Alternative Race/Ethnicity	11.4	0.49	12
Biological Sex	8.7	0.03*°×	3
Binary Primary Language	3.8	0.28	3
Interaction Analyses:			
Race/Ethnicity, Sex	33.5	0.01*°′	18
Use of Alternative Dependent Variable			
Individual Analyses:			
Ever ID Diagnosis	7.9	0.02*°×	2
Current GDD Diagnosis	10.9	< 0.00*°×	2
Previous GDD Diagnosis	4.5	0.11°	2
Previous SL Diagnosis	3.1	0.21	2
Ever Genetic Diagnosis	6.8	0.03*°×	2
Current Other Diagnosis	4.8	0.09°	2
Previous Other Diagnosis	0.2	0.90	2
Current ADHD Diagnosis	13.7	< 0.00*°’	2
Previous ADHD Diagnosis	0.1	0.95	2
Current Anx/OCD/Adj Diagnosis	1.8	0.41	2
Previous Anx/OCD/Adj Diagnosis	0.3	0.85	2
Ever Mood Diagnosis	5.1	0.08°′	2
Alternative Race/Ethnicity	8.3	0.40	8
Binary Primary Language	2.4	0.31	2
Interaction Analyses:			
Race/Ethnicity, Sex	25.9	0.01*°′	12

*indicates statistical significance at $p < 0.05$

°indicates statistical significance following application of the Benjamini-Hochberg correction procedure
´indicates statistically significant test with at least one underfilled contingency table cell
×indicates test for which a cell by cell comparison was also completed

Family-Related Factors. Of the chi-square tests of independence that were completed with the original dependent variable version, none appeared as statistically significant. Caregiver-reported behavior of initial concern emerged as newly significant following application of the Benjamini-Hochberg correction procedure (with a correction level of 0.25), but this factor's association with match of referral and diagnosis was relatively weak in nature. However, of the three tests that were run, two had at least one underfilled cell within the chi-square contingency table, which prompted the researcher to again evaluate potential relationships between the independent variables of interest and the alternative version of the dependent variable.

When levels of the dependent variable were again collapsed and the alternative version was applied, one of the original chi-square analyses emerged as significant. When cell numbers of the contingency table were more fully filled, caregiver-reported behavior of initial concern ($X^2 = 23.9$, $p = 0.02$) appeared to be associated with match of referral and associated diagnosis. Statistical significance was maintained following application of the Benjamini-Hochberg correction procedure, and one additional test (household zip code) emerged as newly significant but weaker in its relation to match of referral and associated diagnosis. However, of these significant chi-square analyses, all continued to have contingency tables with at least one underfilled cell, suggesting that some level of caution should be utilized when interpreting these analyses. For this reason, additional cell by cell comparisons were not completed for any family-related factors. **Table 11** includes a listing of all chi-square tests of independence that were conducted for the family-related factors of interest.

Table 11
Chi-Square Tests of Independence – Family-Related Factors

	Chi-Square Test of Independence		
	X^2	p-value	DF
Use of Original Dependent Variable			
Individual Analyses:			
Caregiver-Reported Behavior of Initial Concern	27.0	0.08°′	18
Household Zip Code	16.4	0.17	12
Family Insurance Type	1.1	0.78	3
Use of Alternative Dependent Variable			
Individual Analyses:			
Caregiver-Reported Behavior of Initial Concern	23.9	0.02*°′	12
Household Zip Code	13.2	0.11°′	8

*indicates statistical significance at $p < 0.05$
°indicates statistical significance following application of the Benjamini-Hochberg correction procedure
′indicates statistically significant test with at least one underfilled contingency table cell

Referring Healthcare Provider-Related Factors. Of the chi-square tests of independence that were conducted with the original dependent variable, one emerged as statistically significant. Practice type of the referring healthcare provider ($X^2 = 16.2$, $p = 0.01$) appeared to be associated with match of referral and associated diagnosis, and this test maintained statistical significance following application of the Benjamini-Hochberg procedure (with a correction level of 0.25). However, all three tests that were run had at least one underfilled cell within the chi-square contingency table, which again prompted the researcher to evaluate associations between the independent variables of interest and the alternative version of the dependent variable. When levels of the original dependent variable were collapsed and the alternative version was utilized, the previously significant chi-square test maintained its significance. Again, practice type of the referring healthcare provider ($X^2 = 15.3$, $p < 0.00$) emerged as an important factor in predicting match of referral and associated diagnosis, and the test maintained statistical significance upon application of the Benjamini-Hochberg correction.

Table 12 includes a listing of all chi-square tests of independence that were examined for the various referring healthcare provider-related factors of interest.

To look more carefully at where potential variations emerged, cell by cell comparisons were conducted to examine differences between expected and observed frequencies. This level of analysis was again saved for only the strongest and most sound relationships, which included one of the chi-square tests of independence with referring healthcare provider variables. **Appendix 3** includes a contingency table with observed and expected frequencies for the analysis of interest. Following visual analysis of the provider practice type contingency table, it emerged that of the individuals who were referred for another disorder and not subsequently diagnosed with ASD, more than expected had a referring healthcare provider who worked in a pediatric specialty care setting. Further, of those who had a mismatched referral and subsequent diagnosis, more of them than expected had a referring provider who worked in a family medicine primary care setting.

Table 12

Chi-Square Tests of Independence – Referring Healthcare Provider-Related Factors

	Chi-Square Test of Independence		
	X^2	p-value	DF
Use of Original Dependent Variable			
Individual Analyses:			
Provider Practice Type	16.2	0.01*°′	6
Provider Practice Zip Code	11.9	0.46	12
Provider Role Type	3.02	0.96	9
Use of Alternative Dependent Variable			
Individual Analyses:			
Provider Practice Type	15.3	< 0.00*°×	4
Provider Practice Zip Code	8.8	0.36	8
Provider Role Type	2.5	0.86	6

*indicates statistical significance at $p < 0.05$
°indicates statistical significance following application of the Benjamini-Hochberg correction procedure
′indicates statistically significant test with at least one underfilled contingency table cell
×indicates test for which a cell by cell comparison was also completed

Multinomial Logistic Regression Analyses

A total of seven multinomial logistic regression analyses were run with the original version of the dependent variable, and four of these analyses included an interaction term. Six of the total analyses examined relationships with child-related factors, and one of these examined associations with family-related factors. The reference condition was category zero of the dependent variable (referral for ASD and subsequent diagnosis of ASD), which indicated a matched referral and diagnosis.

Child-Related Factors. Of the multinomial logistic regression analyses that were conducted to evaluate the predictability of child-related factors, all six emerged as statistically significant at the omnibus level, and two of these continued to present as statistically significant at the condition coefficient level. **Table 13** includes a listing of all multinomial logistic regression analyses and multinomial logistic regression analyses with an interaction term that were completed. Child age at referral was predictive of match of referral and associated diagnosis at both the omnibus level (pseudo $R^2 = 0.018$, $p < 0.00$) and for individuals in category one of the model (referral for another disorder and subsequent diagnosis of ASD; coefficient = -0.026, $p < 0.00$), suggesting that as the child's age at referral increased, the likelihood of being referred for another disorder and receiving a subsequent diagnosis of ASD decreased relative to the reference group of being referred for ASD and receiving a subsequent diagnosis of the disorder. Additionally, child age at diagnosis/feedback was also predictive of match of referral and subsequent diagnosis at both the omnibus level (pseudo $R^2 = 0.019$, $p < 0.00$) and for those in category one of the model (referral for another disorder, subsequent diagnosis of ASD; coefficient = -0.024; $p < 0.00$), suggesting that as the child age at diagnosis/feedback increased,

the likelihood of being referred for another disorder and receiving an ASD diagnosis decreased relative to the reference group of being referred for and diagnosed with ASD. Additionally, the interactions of alternative race/ethnicity and child age at referral (pseudo $R^2 = 0.024$, $p = 0.02$), alternative race/ethnicity and child age at diagnosis/feedback (pseudo $R^2 = 0.027$, $p = 0.01$), biological sex and child age at referral (pseudo $R^2 = 0.029$, $p < 0.00$), and biological sex and child age at diagnosis/feedback (pseudo $R^2 = 0.029$, $p < 0.00$) all appeared to be predictive of match of referral and associated diagnosis at the omnibus level but not at any condition coefficient levels. However, given that no factors were statistically significant at the condition coefficient level, the source of this significance is challenging to discern for the various interaction analyses.

Table 13

Multinomial Logistic Regression – Child-Related Factors Predicting Match of Referral and Associated Diagnosis

	PR^2	Coefficient	SE	p-value
Multinomial Logistic Regression				
Child Age at Referral	0.018	--	--	< 0.00*
Category 1	--	-0.026	0.009	< 0.00*
Category 2	--	-0.000	0.003	0.92
Category 3	--	0.002	0.003	0.62
Child Age at Diagnosis/Feedback	0.019	--	--	< 0.00*
Category 1	--	-0.024	0.008	< 0.00*
Category 2	--	0.000	0.003	0.93
Category 3	--	0.003	0.003	0.39
Multinomial Logistic Regression with Interaction Term				
Alternative Race/Ethnicity, Child Age at Referral	0.024	--	--	0.02*
Category 1				
Alternative Race/Ethnicity	--	0.650	0.468	0.17
Child Age at Referral	--	-0.004	0.019	0.83
Interaction Term	--	-0.0155	0.013	0.25

Category 2				
Alternative Race/Ethnicity	--	-0.098	0.234	0.67
Child Age at Referral	--	-0.004	0.006	0.49
Interaction Term	--	0.002	0.003	0.39
Category 3				
Alternative Race/Ethnicity	--	-0.260	0.243	0.28
Child Age at Referral	--	-0.007	0.006	0.22
Interaction Term	--	0.005	0.003	0.08
Alternative Race/Ethnicity, Child Age at Diagnosis/Feedback	0.027	--	--	0.01*
Category 1				
Alternative Race/Ethnicity	--	1.086	0.625	0.08
Child Age at Diagnosis/ Feedback	--	0.006	0.019	0.77
Interaction Term	--	-0.022	0.015	0.13
Category 2				
Alternative Race/Ethnicity	--	-0.126	0.256	0.62
Child Age at Diagnosis/Feedback	--	-0.003	0.005	0.54
Interaction Term	--	0.002	0.003	0.38
Category 3				
Alternative Race/Ethnicity	--	-0.323	0.267	0.23
Child Age at Diagnosis/Feedback	--	-0.006	0.005	0.28
Interaction Term	--	0.005	0.003	0.07
Biological Sex, Child Age at Referral	0.029	--	--	< 0.00*
Category 1				
Biological Sex	--	-0.126	0.913	0.89
Child Age at Referral	--	-0.126	0.010	0.08
Interaction Term	--	0.000	0.021	0.98
Category 2				
Biological Sex	--	0.564	0.513	0.27
Child Age at Referral	--	-0.000	0.004	0.91
Interaction Term	--	0.000	0.007	0.97
Category 3				
Biological Sex	--	0.929	0.511	0.07
Child Age at Referral	--	0.002	0.004	0.50
Interaction Term	--	-0.003	0.006	0.68
Biological Sex, Child Age at Diagnosis/Feedback	0.029	--	--	< 0.00*
Category 1				
Biological Sex	--	-0.282	1.001	0.78
Child Age at Diagnosis/Feedback	--	-0.025	0.009	0.06

Interaction	--	0.004	0.019	0.85
Category 2				
Biological Sex	--	0.535	0.563	0.34
Child Age at Diagnosis/Feedback	--	0.000	0.004	0.96
Interaction	--	0.001	0.007	0.93
Category 3				
Biological Sex	--	0.852	0.561	0.13
Child Age at Diagnosis/Feedback	--	0.003	0.004	0.41
Interaction	--	-0.001	0.006	0.84

PR^2 = Pseudo R^2
Category 1 = Referral for Another Disorder/Subsequent Diagnosis of ASD
Category 2 = Referral for ASD/No Subsequent Diagnosis of ASD
Category 3 = Referral for Another Disorder/No Subsequent Diagnosis of ASD
*indicates statistical significance at $p < 0.05$

Family-Related Factors. One multinomial logistic regression analysis was conducted to evaluate the predictability of family-related factors. This test did not emerge as statistically significant at the omnibus level (pseudo $R^2 = 0.012$, $p = 0.23$), but did present as statistically significant at the condition coefficient level. Caregiver-reported age of initial concern was marginally predictive of match of referral and associated diagnosis for individuals in category two of the model (referral for ASD and no subsequent diagnosis of ASD; coefficient = 0.028; $p = 0.04$), suggesting that as the caregiver-reported age of initial concern increased, the likelihood of being referred for ASD and not receiving a subsequent diagnosis of ASD increased relative to the reference group of being referred for ASD and receiving a subsequent diagnosis of the disorder. These results are presented in **Table 14**.

Table 14
Multinomial Logistic Regression – Family-Related Factors Predicting Match of Referral and Associated Diagnosis

	PR^2	Coefficient	SE	p-value
Multinomial Logistic Regression				
Caregiver-Reported Age of Initial Concern	0.012	--	--	0.23
Category 1	--	0.007	0.022	0.77
Category 2	--	0.028	0.014	0.04*
Category 3	--	0.016	0.017	0.35

PR^2 = Pseudo R^2
Category 1 = Referral for Another Disorder/Subsequent Diagnosis of ASD
Category 2 = Referral for ASD/No Subsequent Diagnosis of ASD
Category 3 = Referral for Another Disorder/No Subsequent Diagnosis of ASD
*indicates statistical significance at $p < 0.05$

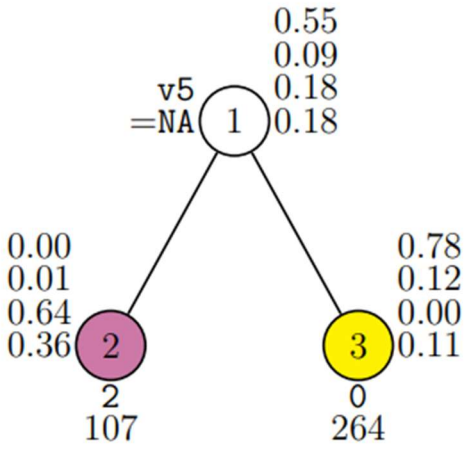
GUIDE Machine Learning Algorithm Analyses

Given that a large number of statistical analyses were planned and conducted, the GUIDE machine learning algorithm was utilized to attend to possible moderation effects and further examine potential relationships between match of referral and subsequent diagnosis and the various child-related, family-related, and referring healthcare provider-related factors of interest. GUIDE attends to all possible predictors in defining a classification tree that splits the sample at nodes with respect to empirically identified levels on variables that are relevant to classification. Unlike the previously reported analyses, splits occurring at subsequent nodes allow GUIDE to also attend to moderating (interaction) effects among variables. Further, GUIDE applies a pruning algorithm to the tree so as to remove potential for increased Type 1 errors due to the large number of predictors evaluated. Thus, application of GUIDE analysis in the current context serves several constructive purposes.

In the current analysis, after inputting the categorical and numerical independent and dependent variables into the algorithm, the factor that emerged as most relevant to predicting match of referral and diagnosis for ASD was the identified level of support (proxy for severity) associated with the ASD diagnosis. Upon review of the prune classification tree in **Figure 1**, the GUIDE algorithm created a split of importance for the "ASD Level of Support" (v5) variable, such that this factor was flagged as being predictive of match of referral and subsequent diagnosis. However, upon further review, the GUIDE analysis appeared to split the study sample based on the total number of missing cases (node 2; n = 107) and included cases (node 3; n =

264) that were reported for this factor, providing a less meaningful classification tree for interpretation purposes.

Figure 1
GUIDE Classification Tree – Research Question 1



Statistical Analyses – Research Question #2

To evaluate the child-related, family-related, and referring healthcare provider-related factors (independent variables) that were associated with timeliness of referral to the diagnostic clinic (dependent variable), a variety of chi-square tests of independence and logistic regression analyses were conducted. As outlined in the methods, Fisher's exact test was utilized in situations where the sample size of 2x2 contingency tables was not large enough to meet assumptions of the chi-square test of independence. The Benjamini-Hochberg statistical correction procedure was again applied to all individual chi-square and exact test analyses to control for false discovery rate, and the GUIDE machine learning algorithm was utilized to examine potential relationships between variables.

Chi-Square Tests of Independence and Fisher's Exact Tests

A total of 53 chi-square analyses were conducted for the second research question, and seven alternative Fisher exact tests were completed when cell sizes of 2x2 contingency tables did not meet the basic assumptions of the chi-square test of independence. Across both statistical analysis types, 48 of the analyses examined associations with child-related factors, five with family-related factors, and seven with referring healthcare provider-related factors.

Child-Related Factors. Of the chi-square analyses that were computed, a total of 21 emerged as statistically significant. Having a previous diagnosis of ASD ($X^2 = 7.23$, $p = 0.01$), a current diagnosis of global developmental delay ($X^2 = 15.24$, $p < 0.00$), a current speech-language diagnosis ($X^2 = 13.57$, $p < 0.00$), or a current non-developmental or non-genetic diagnosis ($X^2 = 29.13$, $p < 0.00$) all appeared to be associated with timeliness of referral to the A&DD Clinic, as well as did ever having a diagnosis of ASD and ID ($X^2 = 26.09$, $p < 0.00$), a diagnosis of ASD and global developmental delay ($X^2 = 11.18$, $p = 0.01$), a diagnosis of ASD and a speech-language delay or disorder ($X^2 = 12.10$, $p = 0.01$), a diagnosis of ASD and ADHD ($X^2 = 70.19$, $p < 0.00$), a diagnosis of ASD and an anxiety, obsessive compulsive, or adjustment disorder ($X^2 = 63.79$, $p < 0.00$), or a diagnosis of ASD and a mood disorder ($X^2 = 18.24$, $p < 0.00$). Regarding service provision, having received early intervention supports ($X^2 = 41.98$, $p < 0.00$), early childcare services ($X^2 = 8.11$, $p < 0.00$), outpatient speech-language therapy ($X^2 = 31.78$, $p < 0.00$), outpatient occupational therapy ($X^2 = 3.91$, $p = 0.04$), outpatient psychological intervention services ($X^2 = 55.21$, $p < 0.00$), or special education/early special education supports ($X^2 = 55.17$, $p < 0.00$) all emerged as being associated with timeliness of referral to the diagnostic clinic, as well as did ever having a diagnosis of ASD and receiving early intervention

supports ($X^2 = 44.76$, $p < 0.00$), a diagnosis of ASD and receiving early childcare services ($X^2 = 9.19$, $p = 0.03$), a diagnosis of ASD and participating in speech-language therapy ($X^2 = 32.75$, $p < 0.00$), a diagnosis of ASD and participating in psychological intervention services ($X^2 = 60.31$, $p < 0.00$), and a diagnosis of ASD and receiving special education/early special education supports ($X^2 = 57.35$, $p < 0.00$). All tests maintained statistical significance upon application of the Benjamini-Hochberg correction procedure (with a correction level of 0.25), and one additional test (ever having a diagnosis of ASD and receiving occupational therapy services) emerged as newly significant but weaker in its association with timeliness of referral to the diagnostic clinic. However, of these significant chi-square analyses, four had contingency tables with at least one underfilled cell, suggesting that some level of caution should be applied when interpreting these analyses. **Table 15** includes a listing of all chi-square tests of independence that were completed for the various child-related factors of interest.

To look more closely at where cell-level differences emerged for the statistically significant chi-square tests of independence, cell by cell comparisons were completed. Again, this level of analysis between expected and observed frequencies was reserved for only the strongest (based on p-value) and most sound (based on sufficient contingency table cell numbers) relationships, which included fifteen of the chi-square analyses with child-related variables. **Appendix 4** includes individual contingency tables with observed and expected frequencies for each analysis of interest.

Following visual analysis of the previous ASD diagnosis contingency table, it emerged that of the individuals who did not have a previous diagnosis of the disorder, more than expected had a timely referral to the diagnostic clinic. Inversely, of those who did have a previous

diagnosis of ASD, more than expected did not have a timely referral to the clinic. Based on review of the contingency table that examined having a current global developmental delay diagnosis, it appeared that of those who had a timely referral, more than expected received a current diagnosis following the diagnostic evaluation process. Of those who did not have a timely referral, fewer than expected received a current global developmental delay diagnosis. For the contingency table that presented having a current speech-language diagnosis, it emerged that of the individuals who had a timely referral, more than expected received a new diagnosis following the evaluation process. For those who did not have a timely referral, fewer than expected did not receive a current speech-language diagnosis. Based on review of the contingency tables that examined enrollment in early intervention, early childcare, or speech-language therapy services, it occurred that for individuals who had a timely referral, more than expected had participated in early intervention, early childcare, or speech-language therapy services. Inversely, for those who did not have a timely referral, fewer than expected had previously participated in early intervention, early childcare, or speech-language therapy services. Additionally, for contingency tables that examined participation in psychological intervention and special education/early special education services, it appeared that of the individuals who did not have a timely referral to the diagnostic clinic, more than expected had received community-based psychological intervention services or special education/early special education in the public school system. Oppositely, for those who did have a timely referral, fewer than expected had received psychological intervention or special education/early special education supports. Following analysis of the ASD ever and global developmental delay ever contingency table, it emerged that regardless of having a previous or current diagnosis of ASD,

individuals who ever had a diagnosis of global developmental delay had more observed timely referrals that expected. Inversely, of those who had never been diagnosed with global developmental delay, fewer than expected had received a timely referral to the diagnostic clinic. For the contingency table that examined ever having ASD and ever having a speech-language diagnosis, it presented that for individuals who had ever been diagnosed with ASD and a speech-language delay or disorder, they were observed to have more timely referrals to the diagnostic clinic than expected. For those who did not have a previous or current diagnosis of ASD but did have a previous or current speech-language diagnosis, these individuals were observed to have as many timely referrals as expected. For those who never had an ASD or speech-language diagnosis, they had more observed timely referrals than expected. Based on analysis of contingency tables that examined ever having a diagnosis of ASD and enrolling in early intervention, early childcare, or speech-language therapy services, it emerged that regardless of having a previous or current diagnosis of ASD, individuals who received early intervention, early childcare, or speech-language therapy had more observed timely referrals than expected, while those who had not received early intervention, early childcare, or community-based speech-language services had more untimely referrals than expected. Finally, for the contingency tables that examined ever having ASD and receiving psychological intervention or special education/early special education services, it appeared that regardless of ever having a diagnosis of ASD, those who had received psychological or special education/early special education supports had more untimely referrals than expected, while those who did not receive these services had more timely referrals to the diagnostic clinic than expected.

Table 15

Chi-Square Tests of Independence – Child-Related Factors

	Chi-Square Test of Independence		
	X^2	p-value	DF
Individual Analyses:			
Current ASD Diagnosis	0.62	0.43	1
Previous ASD Diagnosis	7.23	0.01*°×	1
Current GDD Diagnosis	15.24	< 0.00*°×	1
Previous GDD Diagnosis	0.00	0.97	1
Current SL Diagnosis	13.57	< 0.00*°×	1
Previous SL Diagnosis	0.95	0.33	1
Ever Genetic Diagnosis	0.03	0.87	1
Current Other Diagnosis	29.13	< 0.00*°	1
ASD Level of Support	28.98	2.26°	3
Alternative Race/Ethnicity	3.63	0.46	4
Biological Sex	0.16	0.69	1
Binary Primary Language	0.26	0.61	1
Early Intervention	41.98	< 0.00*°×	1
Early Childcare	8.11	< 0.00*°×	1
Head/Early Head Start	0.01	0.91	1
Therapeutic Support	1.80	0.18	1
Speech-Language Therapy	31.78	< 0.00*°×	1
Occupational Therapy	3.91	0.04*°	1
Physical Therapy	0.71	0.39	1
Psychological Intervention	55.21	< 0.00*°×	1
Special/Early Special Education	55.17	< 0.00*°×	1
Interaction Analyses:			
General Race/Ethnicity, Sex	3.06	0.80	6
Ever ASD, Ever ID	26.09	< 0.00*°,	3
Ever ASD, Ever GDD	11.18	0.01*°×	3
Ever ASD, Ever SL	12.10	0.01*°×	3
Ever ASD, Ever Genetic	1.02	0.79	3
Ever ASD, Ever ADHD	70.19	< 0.00*°,	3
Ever ASD, Ever Anx/OCD/Adj	63.79	< 0.00*°,	3
Ever ASD, Ever Mood	18.24	< 0.00*°,	3
Ever ASD, General Race/Ethnicity	4.96	0.66	7
Ever ASD, Binary Language	2.07	0.56	3
Ever ASD, Early Intervention	44.76	< 0.00*°×	3
Ever ASD, Early Childcare	9.19	0.03*°×	3
Ever ASD, Head/Early Head Start	0.65	0.89	3
Ever ASD, Therapeutic Support	2.36	0.50	3
Ever ASD, Speech-Language Therapy	32.75	< 0.00*°×	3

Ever ASD, Occupational Therapy	6.71	0.08°	3
Ever ASD, Physical Therapy	1.85	0.60	3
Ever ASD, Psychological Intervention	60.31	< 0.00*°×	3
Ever ASD, Special/Early Special Education	57.35	< 0.00*°×	3

*indicates statistical significance at p < 0.05
°indicates statistical significance following application of the Benjamini-Hochberg correction procedure
´indicates statistically significant test with at least one underfilled contingency table cell
×indicates test for which a cell by cell comparison was also completed

For seven instances in which 2x2 contingency table cell sample sizes were insufficient to compute the chi-square test of independence, Fisher's exact test was applied. Of these, all seven analyses presented as statistically significant. Having a previous or current diagnosis of ID ($p < 0.00$), a previous non-developmental or non-genetic diagnosis ($p < 0.00$), a current ADHD diagnosis ($p = 0.01$), a previous ADHD diagnosis ($p < 0.00$), a current anxiety, obsessive compulsive, or adjustment disorder ($p < 0.00$), a previous anxiety, obsessive compulsive, or adjustment disorder ($p < 0.00$), or a previous or current mood disorder ($p < 0.00$) emerged as important factors in predicting timeliness of referral to the diagnostic clinic. Upon application of the Benjamini-Hochberg correction, all seven tests maintained statistical significance. **Table 16** includes a listing of all Fisher's exact tests that were computed for the child-related factors with underfilled 2x2 contingency table cells.

Table 16
Fisher's Exact Tests – Child-Related Factors

	Fisher's Exact Test	
	Odds Ratio	p-value
Ever ID Diagnosis	Infinite	< 0.00*°
Previous Other Diagnosis	124.84	< 0.00*°
Current ADHD Diagnosis	3.89	0.01*°
Previous ADHD Diagnosis	74.15	< 0.00*°
Current Anx/OCD/Adj Diagnosis	13.68	< 0.00*°
Previous Anx/OCD/Adj Diagnosis	Infinite	< 0.00*°
Ever Mood Diagnosis	20.87	< 0.00*°

*indicates statistical significance at p < 0.05

°indicates statistical significance following application of the Benjamini-Hochberg correction procedure

Family-Related Factors. Of the chi-square analyses that were computed, none emerged as statistically significant. Caregiver-reported general behavior of initial concern emerged as newly significant following application of the Benjamini-Hochberg statistical correction procedure (with a correction level of 0.25), but this factor's association with timeliness of referral to the diagnostic clinic was relatively weak in nature and the contingency table had at least one underfilled cell. No additional cell by cell comparisons were completed for any family-related factors. **Table 17** includes a listing of all chi-square tests of independence that were conducted for the family-related factors.

Table 17
Chi-Square Tests of Independence – Family-Related Factors

	Chi-Square Test of Independence		
	X^2	p-value	DF
Individual Analyses:			
General Behavior of Initial Concern	9.61	0.14°′	6
Household Zip Code	5.63	0.23	4
Family Insurance Type	1.99	0.16	1
Interaction Analyses:			
Ever ASD, Household Zip Code	8.11	0.52	9
Ever ASD, Family Insurance Type	4.24	0.24	3

°indicates statistical significance at $p < 0.05$ following application of the Benjamini-Hochberg correction procedure
′indicates statistically significant test with at least one underfilled contingency table cell

Referring Healthcare Provider-Related Factors. Of the chi-square tests of independence that were conducted, three emerged as statistically significant. Practice type ($X^2 = 6.06$, $p = 0.04$) and role type ($X^2 = 7.87$, $p = 0.05$) of the referring healthcare provider appeared to be associated with timeliness of referral to the diagnostic clinic, as well as did ever having a diagnosis of ASD and the type of screening measure reported by the referring healthcare provider ($X^2 = 18.97$, $p < 0.00$). All three tests maintained statistical significance following

application of the Benjamini-Hochberg procedure (with a correction level of 0.25), and one additional test (ever having a diagnosis of ASD and practice type of the referring healthcare provider) emerged as newly significant but less strong in its association with timeliness of referral to the diagnostic clinic. This newly significant test, along with one of the originally significant analyses, had contingency tables with at least one underfilled cell. **Table 18** includes a listing of all chi-square tests of independence that were examined for the various referring healthcare provider-related factors of interest.

In order to look more carefully at where cell-level variations emerged for the statistically significant chi-square tests of independence, cell by cell comparisons were conducted to examine differences between expected and observed frequencies. Again, this level of analysis was saved for only the strongest and most sound relationships, which included two analyses for the referring healthcare providers. **Appendix 4** includes individual contingency tables with observed and expected frequencies for each analysis of interest. Following visual analysis of the provider practice type contingency table, it emerged that individuals who had a referring healthcare provider that worked in a pediatric primary care setting were more likely than expected to have received a timely referral to the clinic, while those who had a referring provider who worked in pediatric specialty care were less likely than expected to receive a timely referral. Additionally, based on review of the provider role type contingency table, it appeared that individuals who had a referring healthcare provider with an MD license were less likely than expected to have received a timely referral to the clinic, while those with DO and NP licensed providers were more likely than expected to have received a timely clinic referral.

Table 18
Chi-Square Tests of Independence – Referring Healthcare Provider-Related Factors

	Chi-Square Test of Independence		
	X^2	p-value	DF
Individual Analyses:			
Provider Practice Type	6.06	0.04*°×	2
Provider Practice Zip Code	6.47	0.17	4
Provider Role Type	7.87	0.05*°×	3
Interaction Analyses:			
Ever ASD, Screening Measure Type	18.97	< 0.00*°′	3
Ever ASD, Provider Practice Type	8.75	0.12°	5
Ever ASD, Provider Practice Zip Code	10.59	0.30	9
Ever ASD, Provider Role Type	8.74	0.27	7

*indicates statistical significance at $p < 0.05$
°indicates statistical significance following application of the Benjamini-Hochberg correction procedure
′indicates statistically significant test with at least one underfilled contingency table cell
×indicates test for which a cell by cell comparison was also completed

Logistic Regression Analyses – Family-Related Factors

A total of two logistic regression analyses were run to evaluate the predictability of family-related factors of interest, and one of these analyses included an interaction term. Of these, both tests emerged as statistically significant at the omnibus level. Caregiver-reported age of initial concern was predictive of timeliness of referral to the diagnostic clinic (odds ratio = 1.071, $p < 0.00$), suggesting that as caregiver-reported age of initial concern increased, the likelihood of receiving a timely referral to the diagnostic clinic also increased. Additionally, the interaction of caregiver-reported age of initial concern and having a previous or current diagnosis of ASD (odds ratio = 0.095, $p < 0.00$) appeared to be predictive of timeliness of referral to the clinic at the omnibus level. However, given that no factors were statistically significant at the condition coefficient level, the source of this significance is challenging to discern. All results are presented in **Table 19**.

Table 19
Logistic Regression – Family-Related Factors Predicting Timeliness of Referral to the Diagnostic Clinic

	Exp(B)	Coefficient	SE	p-value
Logistic Regression				
Caregiver-Reported Age of Initial Concern	1.071	0.069	0.017	p < 0.00*
Logistic Regression with Interaction Term				
Ever ASD Diagnosis, Caregiver-Reported Age of Initial Concern	0.095	--	---	p < 0.00*
Ever ASD Diagnosis	2.314	0.839	0.991	0.39
Caregiver-Reported Age of Initial Concern	1.099	0.094	0.035	0.07
Interaction Term	0.965	-0.036	0.041	0.38

Exp(B) = Odds ratio
*indicates statistical significance at p < 0.05

GUIDE Machine Learning Algorithm Analyses

Given that a large quantity of statistical analyses were planned and conducted, the GUIDE machine learning algorithm was again utilized to attend to possible moderation effects and further examine potential relationships between timeliness of referral to the diagnostic clinic and the various child-related, family-related, and referring healthcare provider-related factors of interest. After inputting the categorical and numerical independent and dependent variables into the algorithm, the factors that emerged as most relevant to predicting timeliness of referral to the diagnostic clinic included having a previous diagnosis of ADHD (v24), having participated in school-based psychological intervention services (v71), having a previous diagnosis of an anxiety, obsessive compulsive, or adjustment disorder (v27), having a current diagnosis of an anxiety, obsessive compulsive, or adjustment disorder (v26), having been enrolled in early intervention services (v49), having participated in community-based speech-language therapy (v57), having a current diagnosis of ADHD (v23), and having a current diagnosis of ID (v6).

The GUIDE classification tree provides a visual representation of conditional logic, where each branch of the tree represents whether a variable was equivalent to a specified value.

Terminal nodes represent a classification with regards to the dependent variable and are color coded (orange circle for referral after the age of three, yellow circle for referral at or before the age of three, etc.). In addition to the value corresponding to the ultimate classification decision, each of these terminal nodes displays two additional pieces of data – the total number of individuals assigned to that classification as a result of the preceding decision points, and the overall accuracy of classification at that point. For example, at the beginning of the tree, having a previous diagnosis of ADHD (v24) produced a referral after the age of three with 98% accuracy for 52 total individuals.

Upon review of the prune classification tree in **Figure 2**, the GUIDE algorithm created an initial split of importance at the "Previous ADHD Diagnosis" (v24) variable and separated those who were previously diagnosed with ADHD (node 2) and those who were not (node 3). For those who did not receive that diagnosis (node 3), another split was made based on "Participation in School-Based Psychological Intervention Services" (v71) and separated individuals who received those services (node 6) and those who did not (node 7). This variable subsequently split the classification tree into two separate branches. The left branch of the tree will be explained first, followed by an explanation of the right branch. For individuals who received school-based psychological intervention (node 6), another split was created at the "Previous Anxiety Disorder/Obsessive Compulsive Disorder/Adjustment Disorder" (v27) variable and parsed those who did (node 12) and did not (node 13) receive that diagnosis. For those who did not receive this diagnosis (node 13), another division was made at the "Current Anxiety Disorder/Obsessive Compulsive Disorder/Adjustment Disorder" (v26) variable, again separating those who did (node 26) and did not (node 27) receive a diagnosis as part of the evaluation process. For those

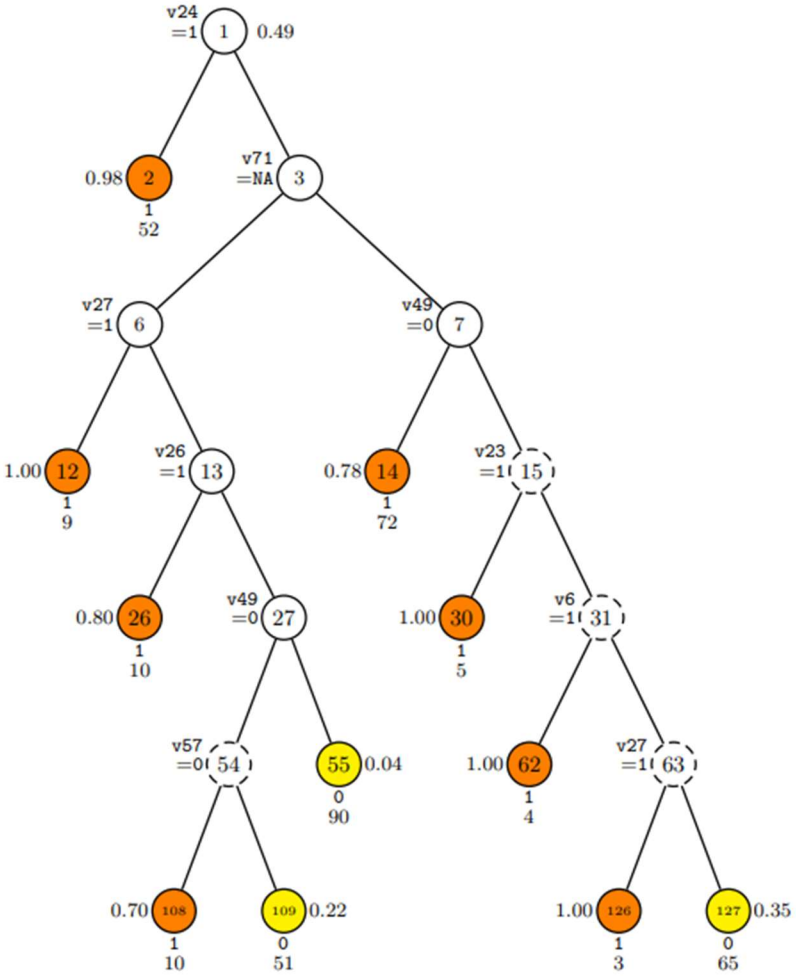
who did not receive this diagnosis (node 27), an additional split was identified at the "Enrollment in Early Intervention Services" (v49) variable and separated individuals who did (node 54) and did not (node 55) participate in early intervention services. For individuals who did receive early intervention supports (node 54), a final split was created at the "Enrollment in Speech-Language Therapy Services" (v57) variable, which separated individuals who did (node 108) and did not (node 109) receive community-based speech-language therapy. To focus on the right branch of the tree, individuals who did not receive school-based psychological intervention services (node 7) had another split at the "Enrollment in Early Intervention Services" (v49) variable, which separated the group into individuals who did (node 14) and did not (node 15) receive early intervention supports. For those who did not receive those services (node 15), a division was created at the "Current ADHD Diagnosis" (v23) variable, again separating those who did (node 30) and did not (node 31) receive a diagnosis as part of the A&DD evaluation process. For those who did not receive this diagnosis (node 31), another split was identified at the "Current ID Diagnosis" (v6) variable. This variable separated individuals who did (node 62) and did not (node 63) receive a diagnosis following participation in the diagnostic evaluation. Finally, for those who did not receive this diagnosis (node 63), a last split was created at the "Previous Anxiety Disorder/Obsessive Compulsive Disorder/Adjustment Disorder" (v27) variable, which parsed those who did (node 126) and did not (node 127) receive a prior diagnosis.

The binary classification tree employed by GUIDE attempts to ask a series of yes or no questions that allow prediction of whether or not a referral to the diagnostic clinic was timely. Of those previously diagnosed with ADHD, 98% went on to be referred to the clinic after the age of three. For individuals who did not receive a previous diagnosis of ADHD, the next decision point

was whether or not they had received school-based psychological services. For those who had received psychological services within the public school system, most of those who had previous or current anxiety, obsessive compulsive, and/or adjustment disorder diagnoses were referred after the age of three, as were those who had early intervention services. For individuals who did not receive school-based psychological services, having received early intervention services or having been currently provided with an ADHD diagnosis, currently provided with an ID diagnosis, or previously provided with an anxiety, obsessive compulsive, or adjustment disorder diagnosis were all associated with an untimely referral to the diagnostic clinic. Cases with timely diagnosis were associated with three potential scenarios. Scenario one was no previous diagnosis of ADHD, no receipt of school-based psychological services, no current diagnosis of ADHD, no current diagnosis of ID, and no previous diagnosis of an anxiety, obsessive compulsive, or adjustment disorder. Scenario two was no previous diagnosis of ADHD, no receipt of school psychological services, no previous or current anxiety, obsessive compulsive, or adjustment disorders, and no receipt of early intervention services. Finally, scenario three involved receipt of early intervention services but no participation in community-based speech-language therapy.

While an understanding of different variables and branching patterns that predict timeliness of referral to the diagnostic clinic are important to consider, it is critical to note that GUIDE does not identify, split, or branch variables based on a fundamental or contextual understanding of those variables. Rather, variables are flagged and parsed apart solely on their association with predicting the dependent variable of interest. Thus, some degree of caution must be utilized when interpreting these results.

Figure 2
GUIDE Classification Tree – Research Question 2



Chapter 4

Discussion

The purpose of this final chapter is to review and interpret findings, implications, and limitations of the current research study. First, this chapter provides a summary of relevant research and highlights the rationale for conducting the study. Next, descriptive characteristics and results for each of the primary research questions are interpreted within the context of the current body of literature. Then, implications for practical application are highlighted, limitations of the current study are outlined, and future research directions are discussed. Finally, an overall summary of findings and significance for the current research is provided.

Overview

Early detection, referral, diagnosis, and treatment are critical to the promotion of positive lifelong trajectories for individuals with ASD, and countless studies outline the importance of these practices in producing significantly improved developmental and functional (Dawson, 2008; Dawson et al., 2009; Fein et al., 2013; Reichow et al., 2012), familial (Gau et al., 2011; Karst & Vaughan Van Hecke, 2012), and societal (Peters-Scheffer et al., 2012) outcomes. Sound screening tools (including the ASQ-3 [Squires & Bricker, 2009] and M-CHAT-R/F [Robins et al., 2009]) and diagnostic assessment measures (including the *Autism Diagnostic Observation Schedule, Second Edition* [ADOS-2; Lord et al., 2012] and *Autism Diagnostic Interview, Revised* [ADI-R; Le Couteur et al., 2003]) exist to support execution of these efforts, and a diagnosis of ASD can be reliably made before the age of two (Centers for Disease Control and Prevention, 2014; Guthrie et al., 2013; Kleinman et al., 2008). Despite this, many pediatric healthcare providers are still not engaging in recommended surveillance and screening procedures or

utilizing consistent diagnostic referral practices (Arunyanart et al., 2012; Hirai et al., 2018; Rea et al., 2019), the average age of initial diagnosis of ASD is well over the age of four, and significant lags exist between time of initial family concern, time of developmental evaluation, and time of diagnosis (Baio et al., 2018; Centers for Disease Control and Prevention, 2020).

To greater understand variables that may promote the pathway toward early detection, referral, and diagnosis of ASD, a variety of studies have sought to examine alternative service settings in which early identification practices could take place (Connecticut Birth to Three System, 2019; Dereu et al., 2012; Janvier et al., 2016; Roberts et al., 2019; Rotholz et al., 2017) and comprehend the various child-level, family-level, and referring healthcare provider-level factors that are associated with achieving these public health goals (Barnard et al., 2017; Brisendine, 2018; Jo et al., 2015; Paul, 2018; Zeleke et al., 2019; Zuckerman et al., 2015). Currently, however, this research has primarily focused on examination of information gathered through retrospective report or analysis of data available at the epidemiologic level. Thus, in line with recommendations for future research to confirm clinical information through examination of electronic health records, the current exploratory study aimed to address these gaps in the literature.

Data for this study was collected using a retrospective electronic health record review of all infant, child, and adolescent patients seen for an initial diagnostic evaluation from September 12, 2019 through September 12, 2020 in the University of Wisconsin – Madison Waisman Center's A&DD Clinic. A total of 371 separate patient health records were included. Of the entire sample, 236 individuals were diagnosed with ASD following the A&DD diagnostic evaluation, an additional 28 individuals had previous diagnoses of ASD prior to participating in

the evaluation process that were retained upon completion of the A&DD assessment, and 107 individuals did not receive a diagnosis of ASD before or following completion of the A&DD evaluation. This exploratory investigation specifically sought to better understand the child-related, family-related, and referring healthcare provider-related factors that contribute to matched referral for and subsequent diagnosis of ASD, as well as identify variables that are particularly related to early identification and referral of children at or under the age of three.

Findings and Interpretation of Results

Descriptive Characteristics

Overall, descriptive characteristics of children and adolescents with ASD in the current study were quite similar to those of individuals from the broader evidence base, suggesting that the current sample is representative of the larger population of individuals with ASD. Of the individuals diagnosed with ASD either during or prior to the diagnostic evaluation process, a significant number had comorbid developmental or psychiatric diagnoses. In line with the current research (American Psychiatric Association, 2013; Hyman et al., 2020; U.S. Department of Health and Human Services, Health, and National Institute on Deafness and Other Communication Disorders, 2014), the most common diagnoses included speech-language delays or disorders (107 total cases), global developmental delays (39 total cases), ADHD (44 total cases), and various anxiety, obsessive compulsive, or adjustment disorders (40 total cases). Again, in alliance with the literature, more males than females were provided with a diagnosis of ASD either prior to the diagnostic evaluation (20 males, 8 females) or following completion of the process (181 males, 55 females), and although the majority of individuals within the current sample were White/Caucasian and Non-Hispanic/Latino (67.6%), rates of ASD were relatively

equivalent for children who were White/Caucasian and Non-Hispanic/Latino (72.9%), Black/African American and Non-Hispanic/Latino (73.2%), and Asian/Pacific Islander and Non-Hispanic/Latino (76.2%) but slightly lower for children who were White/Caucasian and Hispanic/Latino (53.7%; Centers for Disease Control and Prevention, 2020). Further, the majority of children with ASD had initial concerns related to delays, differences, or regression in speech and language skills (19.4% of the total sample), motor skills or global developmental skills (4.9% of the total sample), or early differences in social communication skills, including difficulties with social interaction and eye contact (4.3% of the total sample; Bradley et al., 2016; Werner & Dawson, 2005; Zwaigenbaum et al., 2009; Zwaigenbaum et al., 2013; Zwaigenbaum et al., 2015). On average, families of children with ASD also reported initial concerns around 19 months of age, which again falls well within the average range of initial caregiver-reported ages of concern identified in the literature (Bryson et al., 2007; Centers for Disease Control and Prevention, 2020; Landa et al., 2007; Landa et al., 2012; Wetherby et al., 2004).

Prior to this study, very little information was known about the types of services and therapeutic supports that children and families accessed before the clinical evaluation process for ASD. Following review of the electronic health record, it was found that a large percentage of individuals with ASD from the current sample had received early intervention (Birth to Three; 36.4% of the total sample) and early childcare services (accredited and non-accredited center-based childcare or daycare; 9.9% of the total sample), as well as a variety of therapeutic supports (52.8% of the total sample), prior to accessing diagnostic services through the A&DD Clinic. Of the patients with ASD who received therapeutic support services, the majority participated in either speech-language therapy (36.1% of the total sample) or occupational therapy (25.1% of

the total sample) within the community. These new pieces of evidence support prior research which suggests that early interventionists, early childhood educators, speech-language pathologists, and occupational therapists may all play important supplemental roles in identifying, screening, and referring young children for concerns related to ASD (Campbell et al., 2016; Connecticut Birth to Three System, 2019; Dereu et al., 2012; Larsen et al., 2018; Roberts et al., 2019; Rotholz et al., 2017). These data also indicate the need to ensure that training and education in surveillance and screening for ASD are provided on an ongoing basis and are responsive to the unique qualifications of these different allied healthcare and early childhood professionals (Odom et al., 2012).

Across the entire sample, 55.3% of children and adolescents who were referred for concerns related to ASD received a subsequent diagnosis of the disorder following participation in the clinical evaluation process. Of the remaining patients, a total of 26.9% had an unmatched referral and diagnosis, which encompassed either being referred by a healthcare provider for concerns related to ASD and not receiving a subsequent diagnosis (8.6%) or being referred for other general developmental concerns and subsequently being diagnosed with ASD (18.3%). Thus, although the majority of children who received a diagnosis of ASD following the diagnostic evaluation had a matched referral, a substantial percentage of referrals from healthcare providers were still incorrectly matched. Given the nature of the current health record review study, it was impossible to obtain clarity regarding the barriers to making an accurate referral. However, only 29 total providers out of 371 reported any use of developmental and/or ASD disorder-specific screening measures in the electronic referral, suggesting that a significant number of providers were either not conducting screening as recommended by best practice

guidelines (Filipek et al., 2000; Hyman et al., 2020; Lipkin et al., 2020b; Volkmar et al., 2014b) or were not using screening data to inform their decision-making process even though the AAP recommends universal ASD disorder-specific screening for all children at 18 and 24 months of age (Johnson & Myers, 2007). Failure to incorporate these practices may not only lead to unmatched referrals and subsequent diagnoses (as suggested in the current study), but also increase the potential for referral bias and later age of initial diagnosis (Charman et al., 2001; Oosterling et al., 2010; Warren et al., 2009) and delay accurate identification and initiation of critical supports. Through the promotion of early surveillance, screening, diagnostic assessment, and intervention services, young children can make significant developmental gains in the areas of social, emotional, cognitive, and behavioral functioning (Dawson et al., 2009; Eaves & Ho, 1996).

While caregivers of children diagnosed with ASD in the current study had initial concerns about their child's development, on average, around 19 months of age, these children were not referred to the A&DD Clinic until almost 59 months of age and experienced a total delay of over three years between age of initial concern and age of referral. Then, once children were referred to the diagnostic clinic, the wait time for families was another 4.2 months to be contacted for appointment scheduling, an additional 3.4 months to be seen for a diagnostic intake interview, an additional 1.8 months to complete the diagnostic assessment process, and another half month to receive the ASD diagnosis and relevant treatment recommendations. In accordance with current research findings, children who received a diagnosis of ASD following the diagnostic evaluation process in the present sample waited almost one calendar year between time of referral to the clinic and time of ASD diagnosis (Goin-Kochel et al., 2006; Wiggins et al.,

2006). However, children in the current study were provided with those ASD diagnoses at significantly later ages (68.7 months) than children at the national average (51 months; Centers for Disease Control and Prevention, 2020). Altogether, these data suggest that although early referral and diagnosis are considered best practice for supporting children with ASD, there continue to be significant waiting periods and delays along the identification pathway. These may include inconsistencies in surveillance and screening by referring providers, poor service coordination between referring providers and diagnosticians, and lack of trained diagnosticians with expertise in evaluation of ASD (Durkin et al., 2017; Elder et al., 2016; Kalb et al., 2012; Khowaja et al., 2015; Rea et al., 2019). Additionally, other factors not identified in the electronic health record should be further explored and considered. For example, although caregivers noted concerns, on average, at 19 months, it is unclear what was done about those concerns, if caregivers knew who to contact regarding those concerns, and at what point they shared those concerns with the family's referring healthcare provider.

Match of Referral and Subsequent Diagnosis

Research Question #1: For children who were seen by a professional in a specialty autism diagnostic clinic, what child-related, family-related, and referring healthcare provider-related factors were associated with referral for ASD and subsequent diagnosis of ASD?

Child-Related Factors. To evaluate which child-specific factors were associated with match of referral and subsequent diagnosis, chi-square analyses were conducted with both original (four levels) and alternative (three levels) versions of the dependent variable, and multinomial logistic regression analyses were utilized to evaluate age-related factors of interest. Of the chi-square analyses that were conducted with the original variable version, seven total

factors presented as predictors of match, and three additional tests emerged as marginally associated with referral and subsequent diagnosis. Because all but one of these analyses had a contingency table with at least one underfilled cell, additional tests were run with the alternative variable version to create chi-square tables with more appropriately-filled cells. Following application of the alternative dependent variable, four of the originally underfilled chi-square analyses continued to be significant, one additional test emerged as important, and three analyses presented as weakly associated with match of referral and diagnosis. Across both variable versions, the child-related factors that appeared to be associated with match of referral and diagnosis included *having a previous or current diagnosis of ID, a previous or current diagnosis of global developmental delay, a previous or current genetic diagnosis, a current diagnosis of ADHD, a previous or current diagnosis of a mood disorder, biological sex of the child, and the interaction of race/ethnicity and biological sex of the child*. However, even after applying the alternative dependent variable, various analyses continued to have at least one underfilled contingency table cell, suggesting that some caution is necessary while interpreting the meaning of these results. Thus, while these factors and category levels were introduced to disaggregate data and address gaps in the literature regarding available information at the time of clinic referral and diagnosis (as suggested by Jo et al., 2015 and Zeleke et al., 2019), lack of sufficient cell frequencies limited the results. Because of this, contingency table cell by cell comparisons were reserved for only the strongest and most sound chi-square analyses, which included the *biological sex, previous or current ID diagnosis, current global developmental delay diagnosis, and previous or current genetic diagnosis* factors.

Upon visual analysis of the *biological sex* contingency table, more males than females were found to be referred for and subsequently diagnosed with ASD. This finding aligns with previous results from Brisendine (2018) which suggest that females are less likely than males to receive a diagnosis of ASD and corresponds with more general consensus data which indicate that more males than females are provided with ASD diagnoses (Centers for Disease Control and Prevention, 2020). Of the individuals who were referred for and subsequently diagnosed with ASD, fewer than expected had received either *a previous or current diagnosis of ID,* and fewer than expected had received a *current diagnosis of global developmental delay*. Given that individuals with ASD, ID, and global developmental delay diagnoses have significant overlap in symptom presentation and functional challenges (Mitchell et al., 2013; Polyak et al., 2015; Thurm et al., 2019), it is possible that the children who received a matched referral and diagnosis had symptoms that were more straightforward and only characteristic of ASD, while children with both ASD and ID or ASD and global developmental delay may have fallen into one of the unmatched referral and subsequent diagnosis categories. Additionally, of the individuals who were referred for another disorder and not subsequently diagnosed with ASD, more than expected had received a *previous or current genetic difference or disorder diagnosis*, suggesting that something inherent about having a genetic diagnosis may differentiate between the children who are and are not referred for and diagnosed with ASD. Genetic disorders (such as Down Syndrome and Tuberous Sclerosis, for example) are at times comorbid with ASD, but genetic differences can also be mistaken for the disorder. Interestingly, a recent study found that up to 50% of children with 22q11.2 deletion syndrome (also known as DiGeorge Syndrome) were inaccurately told that they had a diagnosis of ASD when they did not meet full diagnostic criteria

(Angkustsiri et al., 2014). Given that symptoms of 22q11.2 deletion syndrome, such as delayed speech and language development, can also be warning signs of ASD, these diagnostic profiles are relatively easy to confuse. Conversely, in the current study, having been provided with a previous or current genetic diagnosis appeared to have prevented individuals from being incorrectly referred for and classified with ASD. However, future research is critically needed to greater comprehend the significance of these findings, particularly related to the various genetic differences and disorders that were outlined in the current study.

To evaluate the relationship between child age-related factors of interest and match of referral and subsequent diagnosis, multinomial logistic regression analyses were conducted. All six analyses emerged as predictive at the omnibus level, and two continued to present as statistically significant at the condition coefficient level. *Child age at referral and child age at diagnosis* were both predictive of match of referral and associated diagnosis at both the omnibus level and category one of the model (referral for another disorder and subsequent diagnosis of ASD), suggesting that as child age at referral and age at diagnosis increased, individuals were more likely to be referred for and subsequently diagnosed with ASD than be referred for another disorder and subsequently diagnosed with ASD. While symptoms may be present during the early developmental period, these findings align with the notion that behavioral challenges characteristic of ASD may not fully manifest until social demands exceed an individual's ability level or may be masked by compensatory strategies learned early in life (American Psychiatric Association, 2013). Thus, as age of referral and diagnosis increase, behaviors of concern may be more easily identified and flagged for diagnostic referral. Additionally, the *interactions of race/ethnicity and child age at clinic referral, race/ethnicity and child age at clinic diagnosis,*

biological sex and child age at clinic referral, and biological sex and child age at clinic diagnosis all emerged as predictors of match of referral and associated diagnosis at the omnibus level, but did not emerge as significant at any condition coefficient levels. Thus, while there appear to be interactional relationships between race/ethnicity, biological sex, child age at referral, child age at diagnosis, and match of referral and diagnosis, it is difficult to parse apart the directionality of these effects and isolate specific sources of interaction. Using a larger and more diverse sample that includes a longer time period of collected data (such as two to five years, rather than only one), these interactions should be reexamined to learn more about whether traditional patterns of under-representation and/or under-identification of children of racially/ethnically diverse backgrounds and different biological sexes (Centers for Disease Control and Prevention, 2020; Daniels & Mandell, 2014; Jo et al., 2015; Mandell et al., 2002) combined with age to predict match of referral and subsequent diagnosis.

Family-Related Factors. To investigate which family-specific factors were associated with match of referral and diagnosis, chi-square analyses were again conducted with original and alternative versions of the dependent variable, and multinomial logistic regression analyses were conducted to evaluate age-related factors of interest. Of the chi-square analyses that were conducted with the original variable version, none presented as predictors of match, but one test emerged as marginally associated with referral and subsequent diagnosis. Because all but one of these analyses had a contingency table with at least one underfilled cell, additional tests were run with the alternative variable version. Following application of the alternative dependent variable, one of the originally underfilled chi-square analyses emerged as significant, and one additional analysis presented as weakly associated with match of referral and diagnosis. Across both

variable versions, the family-related factors that appeared to be associated with match of referral and diagnosis included *caregiver-reported behavior of initial concern and household zip code.* However, even after applying the alternative dependent variable, the significant chi-square analyses continued to have at least one underfilled contingency table cell, suggesting that some caution is again necessary while interpreting the meaning of these results. Thus, while these factors and category levels were introduced to address gaps in the literature regarding information available at the time of clinic referral and diagnosis (as suggested by Paul, 2018), lack of sufficient cell frequencies greatly limited the results, and additional cell by cell comparisons were not completed for any family-specific factors. Using a larger sample, these relationships should be reevaluated to determine whether specific behaviors of initial concern (such as speech-language, social communication, or motor concerns, as suggested by Kozlowski et al., 2011, Zwaigenbaum et al., 2009, Zwaigenbaum et al., 2013, and Zwaigenbaum et al., 2015) or geographic location of the family predicted match of referral and subsequent diagnosis.

To evaluate the relationship between caregiver-reported age of initial concern and match of referral and subsequent diagnosis, one multinomial logistic regression analysis was conducted. The analysis did not emerge as predictive at the omnibus level but did present as marginally significant at the condition coefficient level. *Caregiver-reported age of initial concern* was marginally predictive of match at category two of the model (referral for ASD and no subsequent diagnosis of ASD), suggesting that as caregiver-reported age of initial concern increased, individuals were slightly less likely to be referred for and subsequently diagnosed with ASD than be referred for ASD and not subsequently diagnosed with the disorder. There may be two potential explanations for these results. First, as age of initial concern increases, the actual

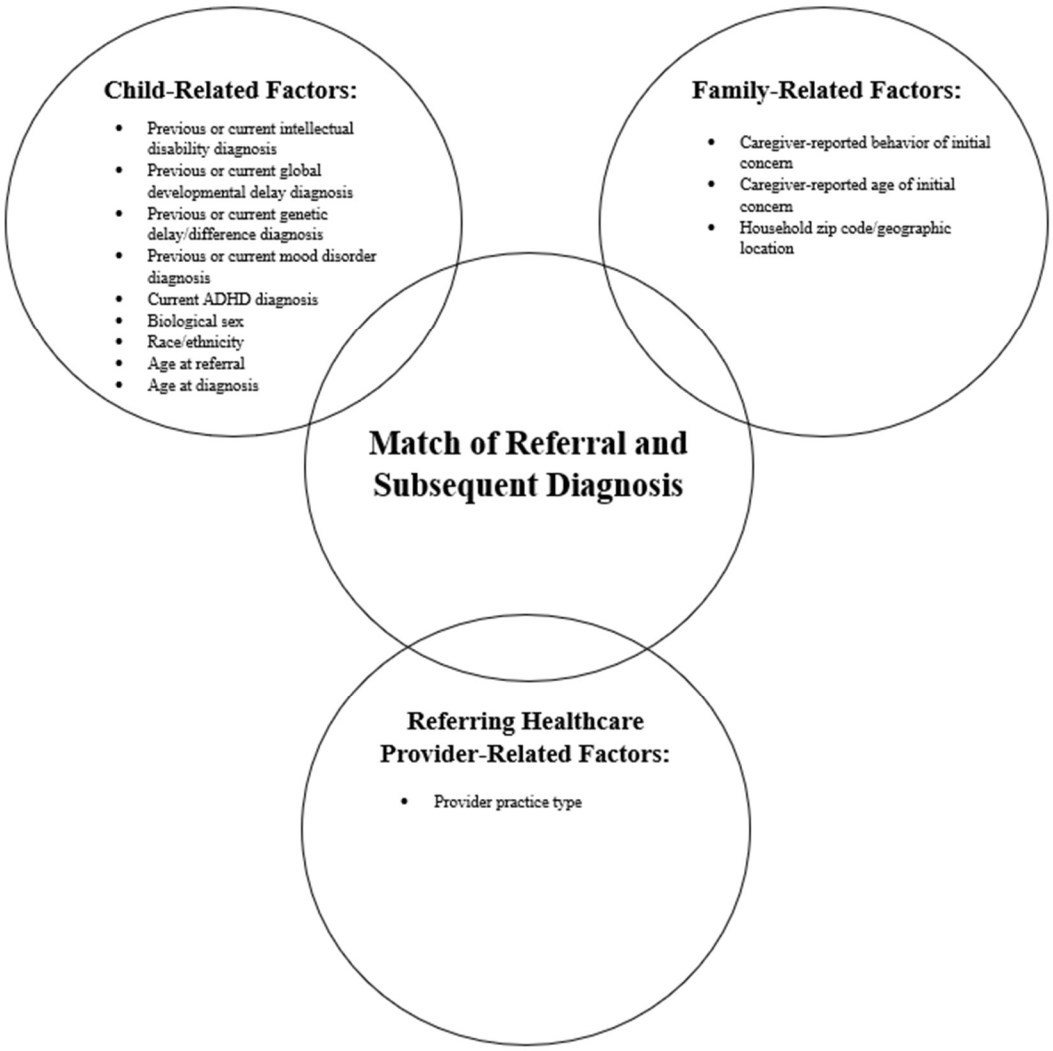
behaviors of concern may be different and inherently less indicative of challenges related to ASD, thus decreasing the likelihood that the clinical referral and subsequent diagnosis are matched for ASD. Alternatively, there may be confounding variables associated with this outcome, such as caregiver information recall bias or unfamiliarity with questions regarding developmental ages and stages (Matheis et al., 2017). It stands to reason that age of initial concern would lead to an earlier and matched diagnosis. However, as previously stated, the action steps that caregivers took, and with whom they shared this information, remains unclear, which again emphasizes the critical need to increase use of screening measures as part of routine pediatric healthcare for all children. Future research is necessary to greater understand these outcomes and learn how increased universal screening practices might provide caregivers with the opportunity to share developmental concerns at the point of initial identification.

Referring Healthcare Provider-Related Factors. To evaluate which exploratory referring healthcare provider-specific factors were associated with match of referral and subsequent diagnosis, chi-square analyses were again conducted with the original and alternative versions of the dependent variable. Of the chi-square analyses that were completed with the original variable version, one factor presented as a predictor of match. However, because all analyses had a contingency table with at least one underfilled cell, additional tests were again run with the alternative variable version to create tables with more appropriately-filled cells. Following application of the alternative dependent variable, the originally underfilled chi-square analysis continued to be significant. Across both variable versions, the only referring healthcare provider-related factor that appeared to be associated with match of referral and diagnosis was *provider practice type*. Upon visual analysis of the *provider practice type* contingency table,

more individuals who were referred for another disorder and not subsequently diagnosed with ASD had a referring healthcare provider who worked in a pediatric specialty care setting, and more individuals who had an unmatched referral and subsequent diagnosis (either referral for ASD and no subsequent diagnosis of ASD, or referral for another disorder and subsequent diagnosis of ASD) than expected had a referring healthcare provider who worked in a family medicine primary care setting. These findings suggest that pediatric specialty providers may be more likely to identify and refer children for developmental concerns outside of ASD more often than primary care providers, as well as highlight that family medicine providers may be more likely to have an unmatched clinical referral (either referring for ASD and the child not being subsequently diagnosed with ASD, or referring for another developmental concern and the child being subsequently diagnosed with ASD). However, given that best practice guidelines for ASD have been specifically designed for pediatric practice settings and family medicine providers are responsible for a significantly greater range of ages and presenting concerns (Bright Futures Steering Committee & Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2006; Fenikile et al., 2015; Filipek et al., 2000; Hyman et al., 2020; Lipkin et al., 2020b; Volkmar et al., 2014b), these findings are not particularly surprising. However, additional research is needed to further delineate the relationships between these factors. **Figure 3** provides a visual summary of all child, family, and referring healthcare provider factors that emerged as predictors of match of referral and diagnosis.

Figure 3

Summary of Predictor Variables Associated with Match of Referral and Subsequent Diagnosis



Timeliness of Clinic Referral

Research Question #2: What detectable differences in child-related, family-related, and referring healthcare provider-related factors exist between children who are referred to a specialty autism diagnostic clinic before/at three years of age versus after three years of age?

Child-Related Factors. To investigate which child-specific factors were associated with timeliness of referral to the diagnostic clinic, chi-square tests of independence were conducted,

and Fisher's exact tests were utilized during situations where the sample size of 2x2 contingency tables was not large enough to meet basic assumptions of the chi-square analysis. Additionally, the GUIDE machine learning algorithm was applied to examine potential relationships between timeliness of referral and the various factors of interest. Of the chi-square analyses that were conducted, 21 total factors and factor combinations emerged as predictors of referral timeliness, and one additional test presented as marginally associated with the dependent variable. The diagnostic-related factors and factor combinations that appeared to be associated with timeliness of referral to the clinic included *having a previous diagnosis of ASD, a current diagnosis of global developmental delay, a current speech-language diagnosis, a current non-developmental or non-genetic diagnosis, and previous or current diagnoses of both ASD and ID, global developmental delay, speech-language delay or disorder, ADHD, anxiety/obsessive compulsive/adjustment disorder, or mood disorder*. The service-related factors and factor combinations that emerged as important to timeliness of referral included *receiving early intervention supports, early childcare services, outpatient speech-language therapy, outpatient occupational therapy, outpatient psychological intervention, special education/early special education services, and a previous or current diagnosis of ASD and receipt of early intervention, early childcare, speech-language therapy, occupational therapy, psychological intervention, or special education/early special education supports*. However, of these analyses, four total had at least one underfilled contingency table cell, suggesting that some caution is necessary while interpreting the significance of these outcomes. Cell by cell comparisons were again reserved for only the strongest and most sound chi-square analyses, which included the *previous ASD diagnosis, current global developmental delay diagnosis, ever ASD and ever global*

developmental delay diagnoses, current speech-language diagnosis, ever ASD and ever speech-language diagnoses, early intervention, ever ASD diagnosis and early intervention, early childcare, ever ASD diagnosis and early childcare, speech-language therapy, ever ASD diagnosis and speech-language therapy, psychological intervention, ever ASD diagnosis and psychological intervention, special education/early special education, and ever ASD diagnosis and special education/early special education factors.

Upon visual analysis of the *previous ASD diagnosis* contingency table, more individuals than expected were referred to the clinic in a timely manner when they did not have a previous diagnosis of ASD, suggesting that not yet having a diagnosis led children to be referred earlier than patients who already had a diagnosis of ASD upon referral. Given the push towards early identification of characteristics associated with ASD and various developmental differences (Hyman et al., 2020; Jimenez-Gomez & Standridge, 2014; Lipkin et al., 2020b; U.S. Department of Health and Human Services, 2020), earlier detection and referral of children without a given disorder makes sense. Of the children who had a timely referral to the diagnostic clinic, more than expected received a *current diagnosis of global developmental delay* following the diagnostic evaluation process. Further, *regardless of having a previous or current diagnosis of ASD*, individuals who had a *previous or current diagnosis of global developmental delay* had more timely referrals to the clinic than expected. Therefore, having symptoms associated with global developmental delay led children to be referred to the clinic earlier than patients who did not demonstrate these characteristics. In order to qualify for a global developmental delay diagnosis, children must demonstrate impairments in two or more developmental domains and be younger than five years of age (American Psychiatric Association, 2013; Jimenez-Gomez &

Standridge, 2014). Thus, the fact that infants or children were referred earlier when they demonstrated these types of developmental challenges and were young in age aligns with information from the current literature base. Of the children who had a timely referral, more than expected also received a *current speech-language diagnosis* after participating in the diagnostic assessment. Given that speech and language differences or delays are often some of the earliest concerns that families have regarding child development (Tager-Flusberg & Kasari, 2013; U.S. Department of Health and Human Services, Health, and National Institute on Deafness and Other Communication Disorders, 2014), this finding implies that infants and children who presented with these concerns were referred earlier and provided with speech-language diagnoses following diagnostic evaluation. When the combination of having a *previous or current diagnosis of both ASD and a speech-language diagnosis* was examined, individuals who had ever been diagnosed with both were more likely to have timely referrals to the diagnostic clinic than expected. Thus, in addition to demonstrating early characteristics of communication challenges, children who additionally showed early signs of ASD were referred earlier than those who did not have concerns related to either of these areas. Speech and language impairments are commonly associated with ASD, and numerous studies have identified that delays in communication and language development are apparent early in life (Landa et al., 2007; Mitchell et al., 2006; Zwaigenbaum et al., 2015). Therefore, the combination of speech and language, social communication, and behavioral difficulties associated with both of these diagnostic profiles appeared to produce an earlier age of referral. Of the individuals who reportedly *accessed early intervention, early childcare, or outpatient speech-language therapy services*, more than expected had received a timely referral to the diagnostic clinic. Additionally,

regardless of having a previous or current diagnosis of ASD, individuals who *previously accessed any of these supports* had more timely referrals. Given that speech-language diagnosis was also associated with earlier age of referral in the current study, these data suggest that infants and children who demonstrated these early challenges were also able to access speech-language therapy services prior to referral. Further, because access to early intervention (Birth to Three) and early childcare services are reserved for very young children (Bailey et al., 2004; Danaher et al., 2006; Laughlin, 2013; National Association for the Education of Young Children, 2003; U.S. Department of Education, 2018), the notion that previous access to such services supported an earlier age of referral makes sense. Of the children who did not have a timely referral to the diagnostic clinic, more than expected had reportedly *accessed community-based psychological intervention or special education/early special education services*. Further, *regardless of having a previous or current diagnosis of ASD*, individuals who *previously accessed either of these supports* had less timely referrals, and those who *had not accessed these supports* prior to the diagnostic evaluation process had more timely referrals. Given that children are not able to access special education or early special education services until after the age of three (U.S. Department of Education, 2018), the finding that children who had previously accessed these services were referred at later ages aligns logistically. Additionally, although children can begin accessing a variety of psychological intervention services (including behavioral or cognitive behavioral therapy, play therapy, or counseling) at very young ages, most individuals do not begin intervention until slightly later in development (Brown et al., 2012; Shafi et al., 2019).

For seven instances in which the 2x2 contingency table cell frequencies were insufficient to run the chi-square analyses, Fisher's exact test was utilized to evaluate the relationship

between diagnostic-related factors of interest and timeliness of referral to the clinic. All seven analyses emerged as predictive of referral timeliness, which included *having a previous or current ID diagnosis, having a previous non-developmental or non-genetic diagnosis, having a current or previous ADHD diagnosis, having a previous or current anxiety, obsessive compulsive, or adjustment disorder diagnosis, and having a previous or current mood disorder diagnosis*. However, given that Fisher's exact test was applied, it is difficult to parse apart where cell-level variations appeared for the various child-specific factors. Using a larger sample, these relationships should be reevaluated with chi-square analyses to determine whether previous or current assignment of the various diagnoses led to earlier or later ages of referral. It would be particularly interesting to examine whether having a previous or current diagnosis of ADHD produced a less timely referral, as recently suggested by Jo and colleagues (2015) and indicated by results from the GUIDE analysis below.

To further evaluate factors associated with timeliness of referral to the diagnostic clinic, the GUIDE machine learning algorithm was applied. Similar to findings from the chi-square analyses and Fisher's exact tests, GUIDE also identified that *having a previous or current diagnosis of ADHD, a previous or current diagnosis of an anxiety, obsessive compulsive, or adjustment disorder, a current diagnosis of ID, and having been enrolled in early intervention or outpatient speech-language therapy services* were all associated with timeliness of referral. Further, having *participated in school-based psychological intervention services* emerged as another factor of importance in predicting timeliness of clinic referral. Across the entire sample of patients, the factor that emerged as ***most predictive of an untimely diagnosis was having a previous diagnosis of ADHD***. This finding may be associated with two potential explanations.

First, symptoms associated with having an ADHD diagnosis, such as hyperactivity and impulsivity, may create an early masking effect of symptoms associated with other diagnoses (as suggested by Jo et al., 2015), which may have led to a later age of referral for other developmental concerns. Second, an ADHD diagnosis cannot be made unless the behaviors of concern are observed in two or more settings, and children must be at least four years of age to receive the diagnosis (American Psychiatric Association, 2013). Thus, if a previous diagnosis of ADHD was present at the time of referral, these individuals were inherently referred at a later age and in a less timely manner. Following that initial split across the entire sample, additional splits predicted timeliness for smaller and smaller subsamples of individuals. A secondary split that emerged as predictive of an untimely diagnosis was having ***previously received school-based psychological services***. Again, as described with findings from the chi-square analyses, children are not able to access school-based psychological services until after at least the age of three (U.S. Department of Education, 2018). Thus, the fact that this variable was ***relatively predictive of an untimely referral*** to the diagnostic clinic makes sense. As additional splits were identified moving down the GUIDE classification tree, predictive effects were observed with increasingly smaller subgroups of the sample and classified as providing less meaningful information toward understanding overall timeliness of referral. With a larger and more diverse sample, additional research is needed to fully comprehend the complexities associated with timeliness of diagnostic referral.

Family-Related Factors. To evaluate which family-specific factors were associated with timeliness of referral to the diagnostic clinic, chi-square and logistic regression analyses were conducted. Of the chi-square analyses that were computed, none presented as predictors of

timeliness, but one test emerged as marginally associated with age at referral. The family-related factor that appeared weakly predictive of timeliness of referral was *caregiver-reported behavior of initial concern*. However, this chi-square analysis had at least one underfilled contingency table cell, suggesting that caution should again be used for interpretation. Thus, while these factors and category levels were examined to address gaps in understanding related to timeliness of referral, lack of sufficient cell frequencies limited the results, and additional cell by cell comparisons were not conducted. Using a larger sample, these predictors should be reexamined to determine whether specific behaviors of initial concern or family geographic locations were associated with timeliness (as suggested by Paul, 2018).

To examine the relationship between family-specific age factors and timeliness of referral, two logistic regression analyses were conducted. Both tests emerged as predictive at the omnibus level. *Caregiver-reported age of initial concern* was predictive of referral timeliness, suggesting that as age of initial concern increased, individuals were more likely to receive a timely referral to the diagnostic clinic. It is possible that slightly later early ages of identified caregiver concern led to more proactive referrals from healthcare providers, where rather than telling families to give development the opportunity to progress or not be concerned about features of developmental delay (Elder et al., 2016), children with slightly later ages of initial concern (say, around two or three years, as opposed to one year of age) may have been referred for diagnostic evaluation in a slightly quicker manner. Additionally, the omnibus *interaction of caregiver-reported age of initial concern and having a previous or current ASD diagnosis* appeared predictive of referral timeliness, but did not emerge as significant at any condition coefficient levels. Thus, while there appears to be an interactional relationship between these

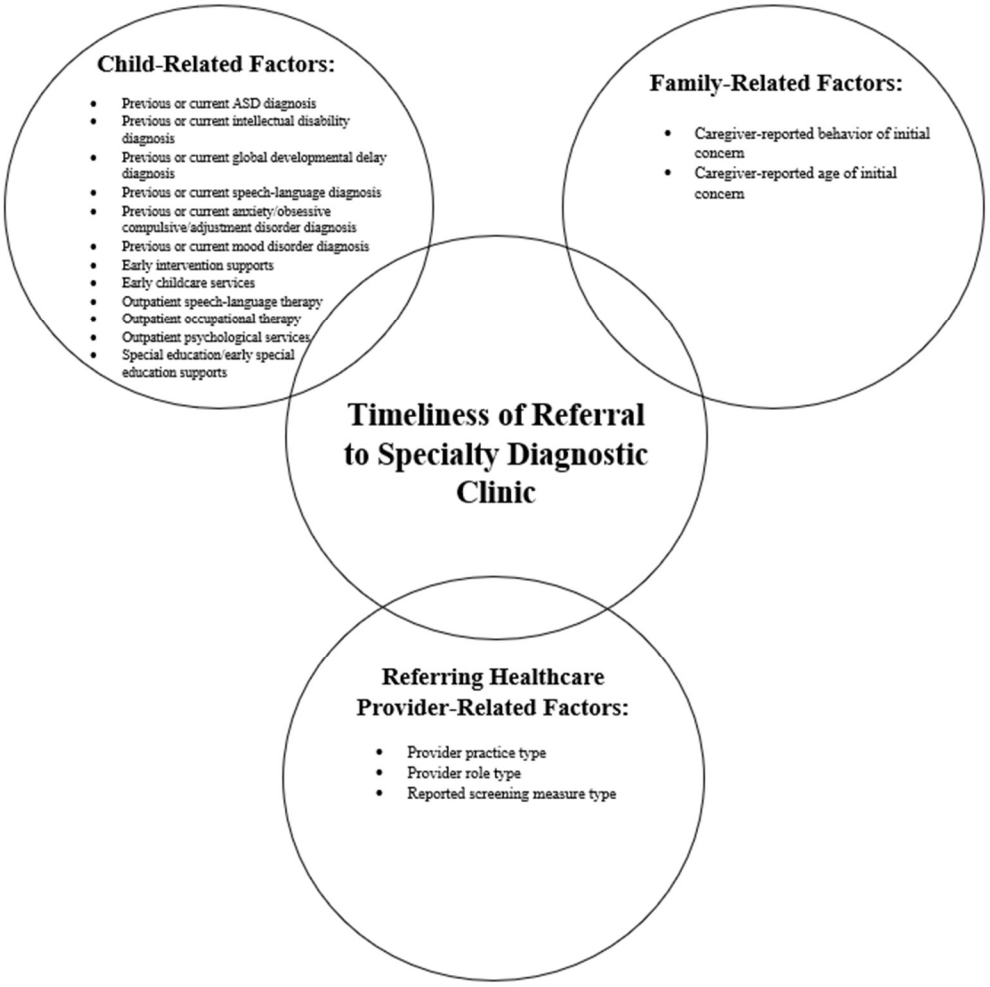
variables, it is difficult to isolate particular sources of interaction. Using a larger and more diverse sample, these analyses should be reexamined to greater understand the directionality of effects and clarify whether earlier ages of caregiver-reported concerns were associated with earlier referral and diagnosis of ASD (as suggested by Paul, 2018).

Referring Healthcare Provider-Related Factors. To understand which exploratory referring healthcare provider-specific factors were associated with timeliness of referral to the diagnostic clinic, a series of chi-square analyses were again completed. Of the chi-square tests that were conducted, three analyses presented as predictors of timeliness, and one test emerged as marginally associated with timeliness of referral. The factors and factor combinations that emerged as important to timeliness of referral included *practice type of the provider, role type of the provider, ever being diagnosed with ASD and type of screening measure reported by the provider, and ever being diagnosed with ASD and practice type of the provider*. However, two of these analyses had at least one underfilled contingency table cell, highlighting the need to use caution while interpreting these outcomes. Cell-level comparisons were again saved for only the strongest and most sound analyses, which included *provider practice type and provider role type*. Upon visual analysis of the *provider practice type* contingency table, more individuals than expected with a timely referral had a referring healthcare provider who worked in a pediatric primary care setting. This finding highlights that pediatric primary care providers were more likely than other types of referring healthcare providers to refer for concerns at an early age, suggesting that aspects of pediatric best practice guidelines (Bright Futures Steering Committee & Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2006; Gardener et al., 2016; Hyman et al., 2020; Lipkin et al., 2020b) were being followed by some

referring healthcare providers in the current study. Following examination of the *provider role type* contingency table, individuals who had a referring healthcare provider with a Medical Doctor (MD) license were less likely than expected to have received a timely referral to the diagnostic clinic, while those with providers having a Doctor of Osteopathy (DO) or Nurse Practitioner (NP) license were more likely than expected to have received a timely referral. It is unclear whether differences in professional training and licensure, scope of practice, or alternative confounding variables (such as area of professional specialization, practice type, recency of degree, or location of degree program) may have produced this outcome. As indicated in Chapter 1, pediatric healthcare providers must have sufficient knowledge of typical and atypical child development, as well as an understanding of measures with which to screen for the early symptoms and warning signs of ASD. However, although use of these screening measures has increased, only 63% of providers in 2016 reported utilizing these recommended practices (Lipkin et al., 2020a). Research indicates that routine use of developmental and ASD disorder-specific screening can increase practitioner knowledge regarding the early warning signs of ASD, reduce bias in referrals, and lower the age of initial ASD diagnosis (Charman et al., 2001; Oosterling et al., 2010; Warren et al., 2009). Similar to the need for additional allied healthcare fields (like speech-language pathology and occupational therapy) to incorporate information and education about ASD into professional training, there is a similar need to infuse these teachings into medical preparation programs (Major, 2015). In fact, a residency training curriculum was recently designed to address this need, called "Autism Case Training (ACT): A Developmental-Behavioral Pediatrics Curriculum," and was developed by the AAP Council on Children with Disabilities Autism Subcommittee (Centers for Disease Control and Prevention, 2014). Ideally,

this self-paced online course would be paired with clinical simulations or training experiences with individuals suspected of or diagnosed with ASD, as well as included with opportunities to practice having discussions with caregivers related to developmental concerns. However, a lack of clarity exists regarding the specific training offerings of MD, DO, and NP preparation programs, and unclear and often conflicting messages from medical training programs regarding surveillance and screening for ASD are known in the field (Siu et al., 2016). Thus, more research is needed to understand how characteristics of referring healthcare providers are related to timeliness of referral and diagnosis, and more efforts are needed to provide clear and solid evidence for universal ASD disorder-specific screening across all pediatric practice settings. **Figure 4** provides a visual summary of all child, family, and referring healthcare provider factors that emerged as predictors of timeliness of referral to the diagnostic clinic.

Figure 4
Summary of Predictor Variables Associated with Timeliness of Referral



Implications for Clinical Practice

Expand Early Identification and Screening Practices Across Settings and Providers

Although clear professional guidelines outline the role that healthcare providers should play in conducting surveillance and screening for ASD, there continue to be significant challenges with practitioners engaging in routine and consistent identification practices (AAP et al., 2006; Hyman et al., 2020; Volkmar et al., 2014b). Thus, results from this study have important implications for the expansion of early identification practices for ASD. In alliance with previous literature suggesting that alternative professionals and service settings may be able to assist in these efforts (Campbell et al., 2016), the current study clearly demonstrates that

children access a variety of therapeutic and support services prior to comprehensive evaluation for ASD. Based on descriptive data from the study, a large percentage of children who were referred to the diagnostic clinic, as well as those who were diagnosed with ASD following the evaluation process, had *previously accessed early intervention programming, early childcare services, outpatient speech-language therapy, and outpatient occupational therapy*. Further, based on statistical analyses, having *previously received these services was associated with timeliness of identification and referral to the diagnostic clinic*. Thus, given that these are settings where children received supports prior to referral along the identification pathway, it is recommended that professionals working in these capacities be recruited and provided with comprehensive professional development in ASD identification to assist with surveillance and screening efforts.

Given identified variations in professional training and perceived readiness across setting types (Branson et al., 2008; Dereu et al., 2012; Larsen et al., 2018; Pizur-Barnekow et al., 2012; Tomlin et al., 2013), it is suggested that early childcare providers working in center-based and NAEYC accredited locations and early intervention professionals with expertise is typical and delayed development be first targeted for potential collaboration and comprehensive professional development in ASD identification. Further, given that many children accessed therapeutic support services prior to referral, it is also strongly recommended that speech-language pathologists and occupational therapists be recruited as potential collaborators and provided with comprehensive professional development in ASD detection, as this information is not universally or sufficiently incorporated into all training preparation programs. These providers not only have content expertise in communication and motor skill development, but also more broadly

understand the intricacies of child development, neurodevelopmental delay and disorder, and clinical assessment and treatment. Through inclusion and recruitment of various individuals working in community-based settings, these professionals can be trained to implement surveillance and screening procedures, recognize potential "red flags" in development, discuss concerns with caregivers and families, and refer children who may be at-risk for ASD to relevant providers. Efforts to develop community-based surveillance, screening, and referral programs that target professionals in early childcare, early intervention, and outpatient therapeutic support settings as partners are likely to increase early identification, early diagnosis, and early intervention services for children with ASD.

Increase Healthcare Provider Screening Practices and Motivation

Pediatric healthcare providers play a critical role in identifying concerns related to ASD and referring children to the appropriate diagnostic services when necessary (Crais et al., 2014; Hagan et al., 2017; Hyman et al., 2020). However, time and again, consistently low levels of providers have been found to actually engage in recommended best practices (Arunyanart et al., 2012; Coury et al., 2017; Hirai et al., 2018), and significant delays continue to exist between time of initial caregiver-reported concerns, time of referral, and time of official ASD diagnosis (Centers for Disease Control and Prevention, 2020). Based on the literature, healthcare providers cite time constraints, lack of familiarity with tools, lack of overall understanding of ASD, and issues with cost and reimbursement as barriers to effective implementation (Anderson et al., 2003; Fenikile et al., 2015; Self et al., 2015). Based on results from the current study, a very small number of healthcare providers (only 7%) were found to report use of developmental and/or ASD disorder-specific screening in the electronic health record. Given the nature of the

study methodology, it is unclear whether these providers had conducted screening and did not include screening results as part of the electronic referral or if they had not engaged in any screening practices in the first place. In order to best target the type of support that is needed, it is important to determine the function or purpose of healthcare provider failure to include screening results in the electronic referral. If providers were found to have completed developmental and/or disorder-specific surveillance and screening as part of routine pediatric care but omitted the early identification findings from the referral, an approach might be taken which considers the provider's perspectives and prior experiences to support acceptance of new recommendations (Rutherford et al., 2016), highlights the value of utilizing data to support decision-making, accountability, and planning (Requejo et al., 2015), and outlines a clear plan and process for how to include surveillance and screening data in the diagnostic referral to increase compliance (Melton et al., 2012). In utilizing this type of intervention, healthcare providers could be trained to understand the importance of early identification practices and the use of screening data to inform the referral and diagnostic evaluation process. Oppositely, if healthcare providers were found to have not conducted developmental and/or disorder-specific surveillance or screening, a critical first step would be to further understand the provider's personal barriers to implementation. Incorporating aspects of previously-described approaches (Melton et al., 2012; Requejo et al., 2015; Rutherford et al., 2016), questions could be asked of providers regarding individual challenges. Depending on barriers that are shared, additional support and/or training should be provided to address the unique challenges of different providers, and methods to motivate and/or incentivize the use of best practices could be considered whenever feasible and possible. Numerous studies have identified the success and minimal risk of early universal

screening for ASD, including a recent article that included Wisconsin-based pediatric healthcare providers (Wieckowski et al., 2021). Out of a total 5,784 infants and toddlers across three states, children were initially screened at 12, 18, or 24 months and then again at 18, 24, or 36 months, respectively. In total, 368 children were subsequently referred and evaluated for an ASD diagnosis. From this study, the authors argued that professionals providing pediatric care should ideally screen for ASD starting at 12 months to facilitate earlier diagnosis of ASD, as well as highlighted that repeated screening (at 18 and 24 months of age) may increase the sensitivity of overall screening outcomes (Wieckowski et al., 2021). Further, as a preventative and systems-level method for preparing new practitioners in the field of healthcare, additional coursework and applied clinical training experiences related to ASD and neurodevelopmental disabilities should be incorporated into professional preparation programs. These efforts should be especially targeted towards providers outside of the pediatric healthcare realm (such as family medicine providers), as previous research has demonstrated that these professionals partake in lower rates of developmental and ASD disorder-specific screening (Mazurek et al., 2021; Moore et al., 2017) and naturally have a broader focus across the lifespan. Additionally, supplemental training programs, such as the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, should be expanded to recruit and include more students who are preparing to become primary care and specialty care medical providers (U.S. Department of Health and Human Services, Health Resources and Service Administration, 2018). Pediatric healthcare professionals currently serve as gatekeepers in initiating the referral process for ASD evaluation, and it is strongly recommended that researchers continue to examine the rationale behind implementation challenges and target these difficulties in a function-based way.

Improve Child Age of Identification and Diagnosis

Finally, results of this study have meaningful implications for improving age of identification, referral, and diagnosis of children with ASD. Based on data reported in the literature, significant delays exist along the pathway toward diagnosis, and evidence of these delays was supported within the current investigation. Although children can be reliably diagnosed with ASD before the age of two (Centers for Disease Control and Prevention, 2020; Guthrie et al., 2013), patients from the current study were not diagnosed until they were an average of 5.73 years (68.7 months) old. For individuals who were referred to the diagnostic clinic and received a new diagnosis of ASD, the average age of referral was 4.89 years (58.7 months). Then, once referred to the clinic, these children waited another 4.2 months to be contacted for scheduling, another 3.4 months to be seen for a diagnostic intake interview, an additional 1.8 months to complete the assessment process, and another 15-16 days to receive the diagnosis. Overall, these children missed out on over three years of potential early intervention services that could have further supported and targeted improvement of social, communication, behavioral, and adaptive functioning skills.

To improve this pathway, factors of significance from the current study could be greater considered during the surveillance, screening, identification, referral, and evaluation process for ASD. Regarding match of referral and diagnosis, *having a previous or current diagnosis of ID, a previous or current diagnosis of global developmental delay, a previous or current genetic diagnosis, a current ADHD diagnosis, a previous or current diagnosis of mood disorder, biological sex, race/ethnicity, child age at referral, and child age at diagnosis* all emerged as child-related factors of importance. *Caregiver-reported behavior of initial concern, household*

zip code, and caregiver-reported age of initial concern appeared as family-related factors of importance, and *provider practice type* emerged as the referring healthcare provider-related factor of importance. Further, regarding timeliness of referral, *having a previous diagnosis of ASD, a previous or current diagnosis of ID, a current diagnosis of global developmental delay, a current speech-language diagnosis, a previous or current diagnosis of ASD, a previous or current anxiety/obsessive compulsive/adjustment disorder, a previous or current mood disorder, a previous or current diagnosis of both ASD and either ID, global developmental delay, speech-language delay or disorder, anxiety/obsessive compulsive/adjustment disorder, or mood disorder, early intervention supports, early childcare services, outpatient speech-language therapy, outpatient occupational therapy, outpatient psychological intervention services, special education/early special education supports, and a previous or current diagnosis of ASD and early intervention supports, early childcare services, speech-language therapy, psychological intervention, or special education/early special education services* all emerged as child-related factors of importance. *Caregiver-reported behavior of initial concern and caregiver-reported age of initial concern* emerged as family-related factors of importance, and *provider practice type, provider role type, and having a previous or current ASD diagnosis and screening measure type* all appeared as referring healthcare provider-related factors of importance. Although these results are obviously in need of future replication and additional research is necessary to further examine cell-level variations, these factors may, in part, hold the key to promoting more matched and timely referral and diagnosis of ASD. This may be achieved by systematically incorporating questions related to these factors on referral forms and/or diagnostic intake interviews, as well as intentionally including results from developmental and ASD disorder-specific screening

measures on all specialty care referrals from referring healthcare providers for diagnostic evaluation services. If this information is not included in referrals, another potential avenue to explore may be specifically asking for and/or requiring ASD disorder-specific screening data prior to the acceptance of a diagnostic referral, which may provide an opportunity for education and encouragement of the necessary medical practice. Such additions may be used to improve the delivery of both primary care and specialty care services.

Limitations and Future Research Directions

Several limitations of this study suggest areas for future research. First, the current investigation was restricted by the sample of clinical data presented in the electronic health record. Available patient data varied significantly from record to record, and the sample population was relatively homogenous in nature (primarily male, White/Caucasian and Non-Hispanic/Latino, and English-speaking). These data were further reduced due to the shutdown of the A&DD Clinic during the state of Wisconsin's initial stay-at-home order effective March 15, 2020 due to the COVID-19 pandemic. This situation also impacted the total number of patients and manner in which many of those included in the current study were evaluated. For context, the total number of A&DD Clinic visits during the 2016-2017 year was 1,756 visits. While it is not possible to determine how many separate electronic health records resulted from those visits, it seems likely that there may have been more than 371 separate health records like those reviewed from the timeline of the current investigation. Thus, the impact of COVID-19 cannot be understated. Second, given that diagnostic evaluation referrals could have come from either in-network (professionals working within the University of Wisconsin – Madison healthcare system) or out-of-network (professionals working in any external healthcare system) healthcare

providers, it is possible that referral information was more or less complete depending on where the referral was placed. Furthermore, the data collection sheet used for the present study did not include information regarding whether a family was seen by one or more providers within the A&DD Clinic for diagnostic evaluation services. These should be noted as limitations of the current study, and future research should seek to consider these components more closely by including them on data collection measures. Third, small and uneven sample sizes for numerous chi-square analyses with the child-related, family-related, and referring healthcare provider-related factors indicated a need to replicate the study using a larger and more diverse sample to increase the reliability, validity, and generalizability of results. When conducting this research, particular attention should be paid to cell-level variations and small-scale trends. These types of analyses will help to best inform an understanding of which factors predict match of referral and diagnosis for ASD, as well as which are associated with timeliness of referral. Additionally, for independent (including primary language and race/ethnicity of the child) and dependent (including match of referral and diagnosis) factors of interest, small cell frequencies in contingency tables prompted the need to combine and collapse variable levels to meet basic test assumptions. While these decisions were necessary for statistical reasons, combining variable levels across numerous independent and dependent variables may have potentially masked patterns of importance, limited an overall ability to identify true differences in the data, and prevented replicability of previous results from the literature. Lack of sufficient data presented in the electronic health record additionally led to elimination of three variables of interest from the study (overall score reported for developmental screening measure; overall score reported for ASD disorder-specific screening measure; overall risk status reported for ASD disorder-specific

screening measure), and a total of four analyses were dropped due to insufficient sample sizes (screening measure type and match of referral/diagnosis; severity of ID diagnosis and timeliness of referral; interaction of ASD ever and caregiver-reported behavior of initial concern and timeliness of referral; screening measure type and timeliness of referral). Fourth, for the second research question, the decision was made to set three years of age (up to three years and eleven months) as the division point between the two levels of the dependent variable, and this variable was conceptualized as being binary in nature. While this dichotomy was determined based on considerations regarding age for qualification and participation in early intervention services, as well as three years being a typical age cutoff for ASD disorder-specific screening measures, these decisions reflect potential limitations of the present investigation. Future research should seek to incorporate alternative age cutoffs to further examine timeliness of referral (such as two years of age and/or four years of age – given when ASD can reliably be diagnosed and/or what the average age of diagnosis currently is), as well as consider operationally defining child age as a continuous (rather than dichotomized) variable. Fifth, while the current retrospective analysis provided unique opportunities to examine preliminary questions of interest, the actual perspectives and practices of referring healthcare providers, diagnostic clinicians, families, and patients were not incorporated. Thus, this should be noted as an additional shortcoming of the study, and future work should more closely investigate these areas through interview and/or survey methodologies in tandem with an objective way to gather and evaluate data. Finally, given that approximately half of the patients included in the study's dataset were provided clinical services during the COVID-19 pandemic, there were inherent differences in service provision and possible limitations in connections that can be drawn between factors of interest

for individuals who were seen prior to and during the course of the pandemic. These potential variations may have included differences in service provision prior to accessing diagnostic services in the clinic (such as early intervention, early childcare, community-based therapeutic supports, and/or special education services), during the referral process, and/or throughout the diagnostic evaluation itself (given that diagnostic services switched from primarily being offered onsite to being offered via telehealth or a hybrid telehealth/onsite delivery model). Thus, to continue examining relationships between these predictor variables and outcomes of interest, further evaluation of all these areas is critically necessary, and future research investigations should examine years of patient data prior to the occurrence of the COVID-19 pandemic for comparison.

Summary

1 in every 54 children in the United States currently meet diagnostic criteria for ASD (Centers for Disease Control and Prevention, 2020). Early identification can lead to early referral, diagnosis, and intervention, which are necessary in the promotion of positive lifelong developmental trajectories for individuals with ASD. Numerous studies have attempted to greater understand elements that promote this pathway, but the current study was one of the first to examine electronic health record data and attempt to comprehend the various child-related, family-related, and referring-healthcare provider-related factors that predicted match of referral and diagnosis for ASD and timeliness of clinical referral. Results indicated that a variety of diagnostic, demographic, historical, and professional licensure variables predicted match of referral and diagnosis, while numerous diagnostic, service provision, historical, professional licensure, and clinical practice factors were associated with timeliness of referral.

Overall, this study contributed to the current literature base in three important ways. First, this study addressed an important gap in the literature by being a first of its kind to examine factors associated with the pathway towards referral and diagnosis for ASD through review of the electronic health record. Rather than relying on parent recall of information in response to epidemiological survey questions, this research examined confirmed patient data that was reported in the health record as part of the diagnostic evaluation process. Second, a variety of alternative service settings and providers were identified as prior points of contact before infants, children, and adolescents were seen in the diagnostic clinic, supporting the notion that screening and early identification efforts may be possible to implement outside of the traditional healthcare setting. In particular, early intervention and early childcare settings, as well as speech-language pathology and occupational therapy service providers, appear to represent ideal collaborators in the critical push toward early identification of children with ASD. Finally, 19 factors and factor combinations uniquely appeared to predict match of referral and diagnosis for ASD, and 35 factors and factor combinations appeared to be associated with timeliness of referral to the diagnostic clinic. These findings suggest that a comprehensive identification, referral, and evaluation process should include assessment of various child-specific, family-specific, and referring healthcare provider-specific factors. Further, these factors may serve as important areas of consideration for healthcare, allied healthcare, and early childhood providers who are contemplating a potential referral for children demonstrating symptoms characteristic of ASD.

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Appendix 1

Electronic Health Record Data Collection Sheet

Subject Identification Number: _____

Child-Related Factors:

Autism Spectrum Disorder Diagnosis? Yes No If yes, current or previous diagnosis? _____

(ASD) If yes, indicated level of support? L1 L2 L3

Intellectual Disability Diagnosis? Yes No If yes, current or previous diagnosis? _____

(ID) If yes, indicated level of severity? Mild Moderate Severe Profound

If yes, full scale score achieved? _____

Global Developmental Delay Diagnosis? Yes No If yes, current or previous diagnosis? _____

(GDD) If yes, full scale score achieved? _____

Speech-Language Disorder Diagnosis? Yes No If yes, current or previous diagnosis? _____

(SL)

Genetic Disorder Diagnosis? Yes No If yes, current or previous diagnosis? _____

If yes, which diagnosis? _____

Other Diagnosis? Yes No If yes, current or previous diagnosis? _____

If yes, which type? ADHD Anxiety Mood

Indicated race/ethnicity of child? _____ Not reported

Sex of child? Male Female

Primary language of the child? _____

Chronological age at time of clinic referral? _____

Chronological age at time of initial clinic contact with family? _____

Chronological age at time of clinic intake interview appointment? _____

Chronological age at time of clinic assessment appointment(s)? _____

Chronological age at time of clinic feedback session? _____

Reported access to early intervention services? Yes No

Reported access to early childcare services? Yes No

Reported access to Head Start/Early Head Start services? Yes No

Reported enrollment in supplemental therapeutic support services? Yes No

If yes, what services? Speech-language therapy Occupational therapy

Physical therapy Psychological intervention

Reported receipt of early special education/special education services? Yes No

If yes, under which primary IDEIA disability category? _____ Not reported

If yes, what services? Speech-language therapy Occupational therapy

Physical therapy Psychological intervention

If participation in developmental screening (see below), overall score reported? _____

If participation in ASD disorder-specific screening (see below), overall score reported? _____

If participation in ASD disorder-specific screening (see below), overall risk status indicated? _____

Family-Related Factors:

Caregiver-reported chronological age of initial concern? _____Not reported

Caregiver-reported behavior of initial concern? _____ Not reported

Family insurance type? _____

Household zip code? _____

Referring Healthcare Provider-Related Factors:

Screening measure administered? Developmental ASD Disorder-Specific Both None

If developmental screening, which measure? _____

If ASD disorder-specific screening, which measure? _____

Practice type of referring healthcare provider? _____ (pediatric, family medicine, etc.)

Clinical practice zip code of referring healthcare provider? _____

Professional role type of referring healthcare provider? MD DO NP PA

Chief concern listed on referral form by referring healthcare provider? ASD ID Developmental Delay (DD)

Dependent Variables:

Match of referral and diagnosis?

Referral Type: ASD Other diagnosis (ID/DD)

Diagnosis Type: ASD Other diagnosis/No diagnosis

Timeliness of referral to clinic?

Referral at or before three years of age

Referral after three years of age

Appendix 2

Data Coding Manual – Variable Definitions and Categories

Child-Related Factors:

- Current assignment of ASD diagnosis (Current ASD Diagnosis)
    - *Definition: Electronic health records will be reviewed to identify whether an infant, child, or adolescent received a DSM-5 diagnosis of ASD following receipt of diagnostic services from the A&DD Clinic.*
    - 0 = no current ASD diagnosis
    - 1 = yes current ASD diagnosis
- Previous assignment of ASD diagnosis (Previous ASD Diagnosis)
    - *Definition: Electronic health records will be searched to determine whether a previous DSM diagnosis of ASD was assigned prior to referral to the A&DD Clinic.*
    - 0 = no previous ASD diagnosis/unknown previous ASD diagnosis
    - 1 = yes previous ASD diagnosis
- Ever assignment of ASD diagnosis (Ever ASD diagnosis)
    - *Definition: Electronic health records will be searched to determine whether a current or previous DSM diagnosis of ASD was assigned. This variable was created to assist with running planned analyses.*
    - 0 = never ASD diagnosis/unknown ever ASD diagnosis
    - 1 = yes ever ASD diagnosis
- Assignment of level of support for ASD diagnosis (ASD Level of Support)
    - *Definition: If a DSM-5 diagnosis of ASD is identified (either from the A&DD Clinic visit or as part of a previous diagnosis), individuals are also assigned a severity level score. These scores include Level 1 ("Requiring support"), Level 2 ("Requiring substantial support"), and Level 3 ("Requiring very substantial support"). If data is extracted regarding current or previous assignment of ASD diagnosis, electronic health records will be examined to determine the indicated level of support associated with the ASD diagnosis. This factor will serve as a proxy for level of severity associated with the diagnosis.*
    - NA = not applicable (for those who didn't receive ASD diagnosis)
    - 1 = Level 1
    - 2 = Level 2
    - 3 = Level 3
    - 4 = not reported in record
- Current assignment of ID diagnosis (Current ID Diagnosis)
    - *Definition: Electronic health records will be reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of ID following receipt of services from the A&DD Clinic.*

    - 0 = no current ID diagnosis
    - 1 = yes current ID diagnosis
- Previous assignment of ID diagnosis (Previous ID Diagnosis)
    - *Definition: Electronic health records will be searched to identify if a prior DSM diagnosis of ID was indicated before the A&DD Clinic visit.*
    - 0 = no previous ID diagnosis
    - 1 = yes previous ID diagnosis
- Ever assignment of ID diagnosis (Ever ID diagnosis)
    - *Definition: Electronic health records will be searched to determine whether a current or previous DSM diagnosis of ID was assigned. This variable was created to assist with running planned analyses.*
    - 0 = never ID diagnosis
    - 1 = yes ever ID diagnosis
- Ever assignment of ASD and ever assignment of ID (Ever ASD, Ever ID)
    - *Interaction variable*
    - 0 = no ASD ever, no ID ever
    - 1 = no ASD ever, yes ID ever
    - 2 = yes ASD ever, no ID ever
    - 3 = yes ASD ever, yes ID ever
- Assignment of severity for ID diagnosis (ID Severity Level)
    - *Definition: Following extraction of data regarding current or previous assignment of ID diagnosis, electronic health records will be examined to determine the indicated level of severity associated with the ID diagnosis.*
    - NA = not applicable (for those who didn't receive ID diagnosis)
    - 1 = mild severity
    - 2 = moderate severity
    - 3 = severe severity
    - 4 = profound severity
    - 5 = not reported in record
- Full scale cognitive assessment score achieved (Full Scale Cognitive Score)
    - *Definition: When a cognitive assessment is conducted with the child or adolescent as part of the A&DD Clinic visit, electronic health record information will be examined to determine the full scale cognitive assessment score that the child or adolescent achieved following an assessment appointment. Scores may be included from the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V), the Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition (WPPSI-IV), the Stanford-Binet Intelligence Scales, Fifth Edition (SB-5), the Leiter International Performance Scale, Third Edition (Leiter-3), or the Differential Ability Scales-II (DAS-II).*
    - NA = not reported/not relevant
    - Full scale score reported

- Current assignment of GDD diagnosis (Current GDD Diagnosis)
    - *Definition: Electronic health records will also be reviewed to identify whether an infant or child received a DSM-5 diagnosis of global developmental delay following receipt of services from the A&DD Clinic.*
    - 0 = no current GDD diagnosis
    - 1 = yes current GDD diagnosis
- Previous assignment of GDD diagnosis (Previous GDD Diagnosis)
    - *Definition: Electronic health records will be searched to identify if a prior DSM diagnosis of global developmental delay was indicated prior to the A&DD Clinic visit.*
    - 0 = no previous GDD diagnosis
    - 1 = yes previous GDD diagnosis
- Ever assignment of ASD and ever assignment of GDD (Ever ASD, Ever GDD)
    - *Interaction variable*
    - 0 = no ASD ever, no GDD ever
    - 1 = no ASD ever, yes GDD ever
    - 2 = yes ASD ever, no GDD ever
    - 3 = yes ASD ever, yes GDD ever
- Full scale developmental quotient score assigned (Full Scale Developmental Score)
    - *Definition: When a developmental assessment is conducted with the infant or child as part of the A&DD Clinic visit, electronic health record information will be reviewed to determine the full scale developmental quotient score that the infant or child achieved following an assessment appointment. Scores may be included from the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III), the Bayley Scales of Infant and Toddler Development, Fourth Edition (Bayley-IV), or the Mullen Scales of Early Learning (Mullen).*
    - NA = not reported/not relevant
    - Full scale score reported
- Current assignment of speech-language diagnosis (Current Speech-Lang Diagnosis)
    - *Definition: Electronic health records will also be examined to identify whether an infant, child, or adolescent received a DSM-5 diagnosis of a speech-language communication disorder following receipt of services from the A&DD Clinic. These diagnoses may include a language disorder/delay (expressive, receptive, or mixed), social pragmatic communication disorder, speech sound disorder, or childhood-onset fluency disorder (stuttering).*
    - 0 = no current s-l diagnosis
    - 1 = yes current s-l diagnosis
- Previous assignment of speech-language diagnosis (Previous Speech-Lang Diagnosis)
    - *Definition: Electronic health records will be searched to identify whether infants, children, or adolescents received a previous DSM diagnosis of a speech-language disorder prior to the A&DD Clinic visit.*

    - 0 = no previous s-l diagnosis
    - 1 = yes previous s-l diagnosis
- Ever assignment of ASD and ever assignment of speech-language diagnosis (Ever ASD, Ever Speech-Lang)
    - *Interaction variable*
    - 0 = no ASD ever, no speech-language diagnosis ever
    - 1 = no ASD ever, yes speech-language diagnosis ever
    - 2 = yes ASD ever, no speech-language diagnosis ever
    - 3 = yes ASD ever, yes speech-language diagnosis ever
- Current assignment of genetic disorder/difference diagnosis (Current Genetic Diagnosis)
    - *Definition: Electronic health records will also be reviewed to identify whether an infant, child, or adolescent received a diagnosis of a genetic disorder/difference following receipt of services from the A&DD Clinic. Some indicated diagnoses/differences may include chromosomal deletions or duplications (such as 16q23.3 deletion, 16q24.1 deletion, 9p21.1 deletion, 1p13.3 duplication, and 3p25.2 duplication).*
    - 0 = no current genetic disorder/difference diagnosis
    - 1 = yes current genetic disorder/difference diagnosis
- Previous assignment of genetic disorder/difference diagnosis (Previous Genetic Diagnosis)
    - *Definition: Electronic health records will be searched to identify if a prior diagnosis of a genetic disorder/difference was indicated. Some previous diagnoses/differences may include Down Syndrome, Doose Syndrome (myoclonic-astatic epilepsy), Cystic Fibrosis, von Willebrand Disease, Mosaic XYY, DiGeorge Syndrome, Cerebral Palsy, Neurofibromatosis, Duane Syndrome, Wiedeman-Steiner Syndrome, Scaff-Yang Syndrome, Eagle-Barrett Syndrome, Hypermobiel Ehler-Danlos Syndrome, Leri-Weill Dyschondrosteosis, Septo-Optic Dysplasia, Tuberous Sclerosis, Neuronal Ceroid-Lipofuscinosis (Type 2), Bohring-Optiz Syndrome, Polymicrogyria, Multiple Endocrine Neoplasia (Type 1), Noonan Syndrome, Stickler Syndrome, and chromosomal deletions or duplications (such as CADP52 deletion, TUBB2A mutation, 22q11.2 deletion, 4q28.1 deletion, 16q21 deletion, 7q36.1 deletion, 10q11.22-23 deletion, 15q13.3 deletion, 16p11.2 deletion, and 16p11.2 duplication).*
    - 0 = no previous genetic disorder/difference diagnosis
    - 1 = yes previous genetic disorder/difference diagnosis
- Ever assignment of genetic disorder/difference diagnosis (Ever Genetic Disorder)
    - *Definition: Electronic health records will be searched to determine whether a current or previous diagnosis of a genetic disorder or difference was assigned. This variable was created to assist with running planned analyses.*
    - 0 = never genetic disorder/difference diagnosis
    - 1 = yes ever genetic disorder/difference diagnosis

- Ever assignment of ASD and ever assignment of genetic disorder/difference diagnosis (Ever ASD, Ever Genetic)
    - *Interaction variable*
    - 0 = no ASD ever, no genetic disorder/difference diagnosis ever
    - 1 = no ASD ever, yes genetic disorder/difference diagnosis ever
    - 2 = yes ASD ever, no genetic disorder/difference diagnosis ever
    - 3 = yes ASD ever, yes genetic disorder/difference diagnosis ever
- Current assignment of other diagnosis (besides ASD/ID/GDD/SL/GD) (Current Other Diagnosis)
    - *Definition: Electronic health records will also be reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of another disorder (besides those previously outlined) following receipt of services from the A&DD Clinic. Indicated diagnoses may include ADHD, a type of anxiety disorder/obsessive compulsive disorder/adjustment disorder, or a type of mood disorder.*
    - 0 = no other current diagnosis
    - 1 = yes other current diagnosis
- Previous assignment of other diagnosis (besides ASD/ID/GDD/SL/GD) (Previous Other Diagnosis)
    - *Definition: Electronic health records will be searched to identify if another DSM diagnosis (besides those previously outlined) was indicated prior to the A&DD Clinic visit. Previous diagnoses may include ADHD, a type of anxiety disorder/obsessive compulsive disorder/adjustment disorder, or a type of mood disorder.*
    - 0 = no other previous diagnosis
    - 1 = yes other previous diagnosis
- Current assignment of other diagnosis – ADHD (Current Other – ADHD)
    - *Definition: Electronic health records will also be reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of ADHD following receipt of services from the A&DD Clinic. ADHD diagnoses may include combined presentation ADHD, predominantly inattentive presentation ADHD, predominantly hyperactive/impulsive presentation ADHD, other specified ADHD, or unspecified ADHD.*
    - 0 = no current ADHD diagnosis
    - 1 = yes current ADHD diagnosis
- Previous assignment of other diagnosis – ADHD (Previous Other – ADHD)
    - *Definition: Electronic health records will be searched to identify if a prior DSM diagnosis of ADHD was indicated prior to the A&DD Clinic visit. Previously assigned ADHD diagnoses may include combined presentation ADHD, predominantly inattentive presentation ADHD, predominantly hyperactive/impulsive presentation ADHD, other specified ADHD, or unspecified ADHD.*

    - 0 = no previous ADHD diagnosis
    - 1 = yes previous ADHD diagnosis
- Ever assignment of ASD and ever assignment of ADHD (Ever ASD, Ever ADHD)
    - *Interaction variable*
    - 0 = no ASD ever, no ADHD ever
    - 1 = no ASD ever, yes ADHD ever
    - 2 = yes ASD ever, no ADHD ever
    - 3 = yes ASD ever, yes ADHD ever
- Current assignment of other diagnosis – Anxiety disorder/Obsessive compulsive disorder/Adjustment disorder (Current Other – Anx/OCD/Adj)
    - *Definition: Electronic health records will be reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of an anxiety disorder, obsessive compulsive disorder, or adjustment disorder following receipt of services from the A&DD Clinic. Anxiety disorder diagnoses may include separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, generalized anxiety disorder, other specified anxiety disorder, or unspecified anxiety disorder. Obsessive compulsive disorder diagnoses may include obsessive compulsive disorder, other specified obsessive compulsive and related disorder, or unspecified obsessive compulsive and related disorder. Adjustment disorder diagnoses may include adjustment disorder.*
    - 0 = no current anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis
    - 1 = yes current anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis
- Previous assignment of other diagnosis – Anxiety disorder/Obsessive compulsive disorder/ Adjustment disorder (Previous Other – Anx/OCD/Adj)
    - *Definition: Electronic health records will be searched to identify if a prior DSM diagnosis of an anxiety disorder was indicated prior to the A&DD Clinic visit. Previously assigned anxiety disorder diagnoses may include separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, generalized anxiety disorder, other specified anxiety disorder, or unspecified anxiety disorder. Previously assigned obsessive compulsive disorder diagnoses may include obsessive compulsive disorder, other specified obsessive compulsive and related disorder, or unspecified obsessive compulsive and related disorder. Previously assigned adjustment disorder diagnoses may include adjustment disorder.*
    - 0 = no previous anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis
    - 1 = yes previous anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis
- Ever assignment of ASD and ever assignment of anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis (Ever ASD, Ever Anx/OCD/Adj)

    - *Interaction variable*
    - 0 = no ASD ever, no anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis ever
    - 1 = no ASD ever, yes anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis ever
    - 2 = yes ASD ever, no anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis ever
    - 3 = yes ASD ever, yes anxiety disorder/obsessive compulsive disorder/adjustment disorder diagnosis ever
- Current assignment of other diagnosis – Mood disorder (Current Other – Mood)
    - *Definition: Electronic health records will be reviewed to identify whether a child or adolescent received a DSM-5 diagnosis of a mood disorder following receipt of services from the A&DD Clinic. Mood disorder diagnoses may include bipolar disorder, disruptive mood dysregulation disorder, major depressive disorder, other specified depressive disorder, or unspecified depressive disorder.*
    - 0 = no current mood disorder diagnosis
    - 1 = yes current mood disorder diagnosis
- Previous assignment of other diagnosis – Mood disorder (Previous Other – Mood)
    - *Definition: Electronic health records will be searched to identify if a prior DSM diagnosis of a mood disorder was indicated prior to the A&DD Clinic visit. Previously assigned mood disorder diagnoses may include bipolar disorder, disruptive mood dysregulation disorder, major depressive disorder, other specified depressive disorder, or unspecified depressive disorder.*
    - 0 = no previous mood disorder diagnosis
    - 1 = yes previous mood disorder diagnosis
- Ever assignment of other diagnosis – Mood disorder (Ever Other – Mood)
    - *Definition: Electronic health records will be searched to determine whether a current or previous DSM diagnosis of a mood disorder was assigned. This variable was created to assist with running planned analyses.*
    - 0 = never mood disorder diagnosis
    - 1 = yes ever mood disorder diagnosis
- Ever assignment of ASD and ever assignment of mood disorder (Ever ASD, Ever Mood)
    - *Interaction variable*
    - 0 = no ASD ever, no mood disorder ever
    - 1 = no ASD ever, yes mood disorder ever
    - 2 = yes ASD ever, no mood disorder ever
    - 3 = yes ASD ever, yes mood disorder ever
- Race of child (Race Specific)
    - *Definition: Electronic health records will be reviewed to determine the race of all infants, children, and adolescents seen by clinicians in the A&DD Clinic.*
    - NA = information not available

    - 1 = White/Caucasian
    - 2 = Black/African American
    - 3 = Asian/Asian American
    - 4 = American Indian/Alaska Native
    - 5 = Native Hawaiian/Other Pacific Islander
    - 6 = Other Race (biracial, multiracial)
- Ethnicity of child (Ethnicity Specific)
    - *Definition: Electronic health records will be reviewed to determine the ethnicity of all infants, children, and adolescents seen by clinicians in the A&DD Clinic.*
    - 0 = Non-Hispanic/Latino
    - 1 = Hispanic/Latino
- Race/ethnicity of child (Race/Ethnicity Specific)
    - *Definition: Electronic health records will be reviewed to determine the combined race/ethnicity of all infants, children, and adolescents seen by clinicians in the A&DD Clinic.*
    - NA = information not available
    - 1 = White/Caucasian, Non-Hispanic/Latino
    - 2 = White/Caucasian, Hispanic/Latino
    - 3 = Black/African American, Non-Hispanic/Latino
    - 4 = Black/African American, Hispanic/Latino
    - 5 = Asian/Asian American, Non-Hispanic/Latino
    - 6 = Asian/Asian American, Hispanic/Latino
    - 7 = American Indian/Alaska Native, Non-Hispanic/Latino
    - 8 = American Indian/Alaska Native, Hispanic/Latino
    - 9 = Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino
    - 10 = Native Hawaiian/Other Pacific Islander, Hispanic/Latino
    - 11 = Other Race, Non-Hispanic/Latino
    - 12 = Other Race, Hispanic/Latino
- Alternative race/ethnicity of child (New Race/Ethnicity)
    - *Definition: Electronic health records will be reviewed to determine the combined race/ethnicity of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. This variable was created to assist with running planned analyses, as many of the specific race/ethnicity groups included above did not have sufficient case numbers.*
    - NA = information not available
    - 1 = White/Caucasian, Non-Hispanic/Latino
    - 2 = White/Caucasian, Hispanic/Latino
    - 3 = Black/African American, Non-Hispanic/Latino
    - 4 = Asian/Asian American, Non-Hispanic/Latino
    - 5 = Other (Black/African American, Hispanic/Latino; Asian/Asian American, Hispanic/Latino; American Indian/Alaska Native, Non-Hispanic/Latino;

American Indian/Alaska Native, Hispanic/Latino; Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino; Native Hawaiian/Other Pacific Islander, Hispanic/Latino; 11 = Other Race, Non-Hispanic/Latino; Other Race, Hispanic/Latino)

- Sex of child (Biological Sex)
  - *Definition: Electronic health records will be examined to determine the biological sex of all infants, children, and adolescents seen by clinicians in the A&DD Clinic.*
  - 0 = male sex
  - 1 = female sex
- Race/ethnicity of child and sex of child (Specific Race/Ethnicity, Sex)
  - *Interaction variable*
  - NA = information not available (due to race/ethnicity of child being unavailable)
  - 1 = White/Caucasian, Non-Hispanic/Latino, male sex
  - 2 = White/Caucasian, Non-Hispanic/Latino, female sex
  - 3 = White/Caucasian, Hispanic/Latino, male sex
  - 4 = White/Caucasian, Hispanic/Latino, female sex
  - 5 = Black African American, Non-Hispanic/Latino, male sex
  - 6 = Black/African American, Non-Hispanic/Latino, female sex
  - 7 = Black/African American, Hispanic/Latino, male sex
  - 8 = Black/African American, Hispanic/Latino, female sex
  - 9 = Asian/Asian American, Non-Hispanic/Latino, male sex
  - 10 = Asian/Asian American, Non-Hispanic/Latino, female sex
  - 11 = Asian/Asian American, Hispanic/Latino, male sex
  - 12 = Asian/Asian American, Hispanic/Latino, female sex
  - 13 = American Indian/Alaska Native, Non-Hispanic/Latino, male sex
  - 14 = American Indian/Alaska Native, Non-Hispanic/Latino, female sex
  - 15 = American Indian/Alaska Native, Hispanic/Latino, male sex
  - 16 = American Indian/Alaska Native, Hispanic/Latino, female sex
  - 17 = Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino, male sex
  - 18 = Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino, female sex
  - 19 = Native Hawaiian/Other Pacific Islander, Hispanic/Latino, male sex
  - 20 = Native Hawaiian/Other Pacific Islander, Hispanic/Latino, female sex
  - 21 = Other Race, Non-Hispanic/Latino, male sex
  - 22 = Other Race, Non-Hispanic/Latino, female sex
  - 23 = Other Race, Hispanic/Latino, male sex
  - 24 = Other Race, Hispanic/Latino, female sex
- Race/ethnicity of child and ASD ever (Specific Race/Ethnicity, Ever ASD)
  - *Interaction variable*
  - 0 = information not available (due to race/ethnicity of child being unavailable)
  - 1 = White/Caucasian, Non-Hispanic/Latino, no ASD ever

    - 2 = White/Caucasian, Non-Hispanic/Latino, yes ASD ever
    - 3 = White/Caucasian, Hispanic/Latino, no ASD ever
    - 4 = White/Caucasian, Hispanic/Latino, yes ASD ever
    - 5 = Black African American, Non-Hispanic/Latino, no ASD ever
    - 6 = Black/African American, Non-Hispanic/Latino, yes ASD ever
    - 7 = Black/African American, Hispanic/Latino, no ASD ever
    - 8 = Black/African American, Hispanic/Latino, yes ASD ever
    - 9 = Asian/Asian American, Non-Hispanic/Latino, no ASD ever
    - 10 = Asian/Asian American, Non-Hispanic/Latino, yes ASD ever
    - 11 = Asian/Asian American, Hispanic/Latino, no ASD ever
    - 12 = Asian/Asian American, Hispanic/Latino, yes ASD ever
    - 13 = American Indian/Alaska Native, Non-Hispanic/Latino, no ASD ever
    - 14 = American Indian/Alaska Native, Non-Hispanic/Latino, yes ASD ever
    - 15 = American Indian/Alaska Native, Hispanic/Latino, no ASD ever
    - 16 = American Indian/Alaska Native, Hispanic/Latino, yes ASD ever
    - 17 = Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino, no ASD ever
    - 18 = Native Hawaiian/Other Pacific Islander, Non-Hispanic/Latino, yes ASD ever
    - 19 = Native Hawaiian/Other Pacific Islander, Hispanic/Latino, no ASD ever
    - 20 = Native Hawaiian/Other Pacific Islander, Hispanic/Latino, yes ASD ever
    - 21 = Other Race, Non-Hispanic/Latino, no ASD ever
    - 22 = Other Race, Non-Hispanic/Latino, yes ASD ever
    - 23 = Other Race, Hispanic/Latino, no ASD ever
    - 24 = Other Race, Hispanic/Latino, yes ASD ever
- General race/ethnicity of child and sex of child (General Race/Ethnicity, Sex)
    - *Interaction variable*
    - NA = information not available (due to race/ethnicity of child being unavailable)
    - 1 = white, non-Hispanic/Latino, male sex
    - 2 = white, non-Hispanic/Latino, female sex
    - 3 = white, Hispanic/Latino, male sex
    - 4 = white, Hispanic/Latino, female sex
    - 5 = non-white, non-Hispanic/Latino, male sex
    - 6 = non-white, non-Hispanic/Latino, female sex
    - 7 = non-white, Hispanic/Latino, male sex
    - 8 = non-white, Hispanic/Latino, female sex
- General race/ethnicity of child and ASD ever (General Race/Ethnicity, Ever ASD)
    - *Interaction variable*
    - NA = information not available (due to race/ethnicity of child being unavailable)
    - 1 = white, non-Hispanic/Latino, no ASD ever
    - 2 = white, non-Hispanic/Latino, yes ASD ever
    - 3 = white, Hispanic/Latino, no ASD ever
    - 4 = white, Hispanic/Latino, yes ASD ever

    - 5 = non-white, non-Hispanic/Latino, no ASD ever
    - 6 = non-white, non-Hispanic/Latino, yes ASD ever
    - 7 = non-white, Hispanic/Latino, no ASD ever
    - 8 = non-white, Hispanic/Latino, yes ASD ever
- Primary language of child (Specific Primary Language)
    - *Definition: Electronic health records will be reviewed to determine the primary language of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. Primary language of the child may include English, Spanish, American Sign Language, Mandarin, Albanian, Arabic, or Cambodian.*
    - 0 = English language
    - 1 = Spanish language
    - 2 = American Sign Language
    - 3 = Mandarin
    - 4 = Albanian
    - 5 = Arabic
    - 6 = Cambodian
- General primary language of child (General Primary Language)
    - *Definition: Electronic health records will be reviewed to determine the primary language of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. Primary language of the child may include English language, Spanish language, or other language (American Sign Language, Mandarin, Albanian, Arabic, or Cambodian).*
    - 0 = English language
    - 1 = Spanish language
    - 2 = other language (American Sign Language, Mandarin, Albanian, Arabic, Cambodian)
- Binary primary language of child (Binary Primary Language)
    - *Definition: Electronic health records will be reviewed to determine the primary language of all infants, children, and adolescents seen by clinicians in the A&DD Clinic. Primary language of the child may include English language or other language (Spanish, American Sign Language, Mandarin, Albanian, Arabic, or Cambodian).*
    - 0 = English language
    - 1 = other language (Spanish, American Sign Language, Mandarin, Albanian, Arabic, Cambodian)
- Binary primary language of child and ASD ever (Binary Primary Language, Ever ASD)
    - *Interaction variable*
    - 0 = English language, no ASD ever
    - 1 = English language, yes ASD ever
    - 2 = other language (Spanish, American Sign Language, Mandarin, Albanian, Arabic, Cambodian), no ASD ever

    - 3 = other language (Spanish, American Sign Language, Mandarin, Albanian, Arabic, Cambodian), yes ASD ever
- Child's age at time of clinic referral (Child Age at Referral)
    - *Definition: Information from electronic health records will be reviewed to determine the infant, child, or adolescent's chronological age at the time of referral to the A&DD Clinic.*
    - Year and month of age – converted into total months of age
- Child's age at time of initial clinic contact with family (Child Age at Initial Contact)
    - *Definition: Information from electronic health records will be examined to determine the infant, child, or adolescent's chronological age at the time of initial A&DD Clinic contact with the family for scheduling or referral clarification purposes.*
    - Year and month of age – converted into total months of age
- Child's age at time of clinic intake interview appointment (Child Age at Intake Interview)
    - *Definition: Information from electronic health records will be reviewed to determine the infant, child, or adolescent's chronological age at the time of the initial clinic intake interview appointment in the A&DD Clinic.*
    - Year and month of age – converted into total months of age
- Child's age at time of clinic assessment appointment (Child Age at Assessment)
    - *Definition: Information from electronic health records will be examined to determine the infant, child, or adolescent's chronological age at the time of the assessment appointment(s) in the A&DD Clinic. For any individuals who had more than one assessment appointment, the child's age at the latest appointment date will be recorded.*
    - Year and month of age – converted into total months of age
- Child's age at time of clinic diagnosis (feedback session) (Child Age at Feedback)
    - *Definition: Information from electronic health records will be reviewed to determine the infant, child, or adolescent's chronological age at the time of the diagnostic feedback session in the A&DD Clinic.*
    - Year and month of age – converted into total months of age
- Reported enrollment in early intervention services (Birth to Three) (Early Intervention Enrollment)
    - *Definition: Information from electronic health records will be searched to determine whether infants, children, or adolescents qualified and were enrolled in early intervention (Part C) services prior to diagnosis. Enrollment in these services may have occurred at any time.*
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
- Reported enrollment in early intervention services (Birth to Three) and ASD ever (Early Intervention, Ever ASD)
    - *Interaction variable*

    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
- Reported enrollment in early childcare services (Early Childcare Enrollment)
    - *Definition: Information from electronic health records will be reviewed to determine whether infants, children, or adolescents were enrolled in early childcare services prior to diagnosis. Enrollment in these services may have occurred at any time, and early childcare services may include accredited childcare programs, non-accredited childcare programs, home-based childcare programs, or center-based childcare programs.*
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
- Reported enrollment in early childcare services and ASD ever (Early Childcare, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
- Reported enrollment in Head Start/Early Head Start services (HS/EHS Enrollment)
    - *Definition: Information from electronic health records will be examined to determine whether infants, children, or adolescents enrolled in Head Start and/or Early Head Start services prior to diagnosis. Enrollment in these services may have occurred at any time.*
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
- Reported enrollment in Head Start/Early Head Start services and ASD ever (HS/EHS, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
- Reported enrollment in supplemental therapeutic support services (Therapeutic Support Enrollment)
    - *Definition: Information from electronic health records will be searched to determine whether infants, children, or adolescents were enrolled in any supplemental therapeutic support services prior to diagnosis. Access to these services may have occurred at any time and may include services such as speech-language therapy, occupational therapy, physical therapy, or psychological*

intervention. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) is not counted as "reported enrollment in services" here.
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
- Reported enrollment in supplemental therapeutic support services and ASD ever (Therapeutic Support, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
- If reported enrollment in supplemental therapeutic support services – reported enrollment in speech-language therapy (Speech-Lang Therapy)
    - *Definition: Following review of information related to potential enrollment in supplemental therapeutic support services, further examination will determine whether infants, children, or adolescents were enrolled in speech-language therapy services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) is not counted as "reported enrollment in services" here.*
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- Reported enrollment in speech-language therapy and ASD ever (Speech-Lang Therapy, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- If reported enrollment in supplemental therapeutic support services – reported enrollment in occupational therapy (Occupational Therapy)
    - *Definition: Following review of information related to potential enrollment in supplemental therapeutic support services, further examination will determine whether infants, children, or adolescents were enrolled in occupational therapy services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an intake evaluation (but not yet receiving*

access to services) or only attending one session (and then declining or refusing future services) is not counted as "reported enrollment in services" here.
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- Reported enrollment in occupational therapy and ASD ever (Occupational Therapy, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- If reported enrollment in supplemental therapeutic support services – reported enrollment in physical therapy (Physical Therapy)
    - *Definition: Following review of information related to potential enrollment in supplemental therapeutic support services, further examination will determine whether infants, children, or adolescents were enrolled in physical therapy services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) is not counted as "reported enrollment in services" here.*
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- Reported enrollment in physical therapy and ASD ever (Physical Therapy, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- If reported enrollment in supplemental therapeutic support services – reported enrollment in psychological intervention (Psych Intervention)
    - *Definition: Following review of information related to potential enrollment in supplemental therapeutic support services, further examination will determine whether infants, children, or adolescents were enrolled in psychological*

intervention services prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time, and potential services may include cognitive behavioral intervention, EIBI, applied behavior analysis treatment, behavioral intervention, play-based therapy, or counseling intervention. Participating in an intake evaluation (but not yet receiving access to services) or only attending one session (and then declining or refusing future services) is not counted as "reported enrollment in services" here.
    - 0 = no reported enrollment
    - 1 = yes reported enrollment
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- Reported enrollment in psychological intervention and ASD ever (Psych Intervention, Ever ASD)
    - *Interaction variable*
    - 0 = no reported enrollment, no ASD ever
    - 1 = no reported enrollment, yes ASD ever
    - 2 = yes reported enrollment, no ASD ever
    - 3 = yes reported enrollment, yes ASD ever
    - NA = not applicable (if no reported enrollment in supplemental therapeutic support services)
- Reported receipt of early special education/special education services (SPED/Early SPED)
    - *Definition: Information from electronic health records will be searched to determine whether children or adolescents qualified and participated in any early special education (early childhood) or special education services through Part B of IDEIA in the public education system prior to diagnosis in the A&DD Clinic. Access to these services may have occurred at any time. Participating in an evaluation (but not qualifying or not yet receiving access to services) is not counted as "reported receipt of services" here.*
    - 0 = no reported receipt
    - 1 = yes reported receipt
- Reported receipt of early special education/special education services and ASD ever (SPED/Early SPED, Ever ASD)
    - *Interaction variable*
    - 0 = no reported receipt, no ASD ever
    - 1 = no reported receipt, yes ASD ever
    - 2 = yes reported receipt, no ASD ever
    - 3 = yes reported receipt, yes ASD ever
- If reported receipt of early special education/special education services – indicated IDEA disability classification for services (primary disability listed) (IDEA Disability Classification)

    - *Definition: Following review of information related to potential receipt of early special education or special education services, further examination will determine the primary disability classification that children were assigned in the public education system under Part B of IDEIA.*
    - 0 = IDEIA disability classification not reported
    - 1 = ASD
    - 2 = ID
    - 3 = SLD
    - 4 = OHI
    - 5 = EBD
    - 6 = Speech or language impairment
    - 7 = Deafness
    - 8 = Hearing impairment
    - 9 = Significant developmental delay
    - NA = Not applicable (if no reported receipt of early special education/special education services)
- If reported receipt of early special education/special education services – reported participation in speech-language therapy services through school system (School-Based Speech Therapy)
    - *Definition: Following review of information related to potential receipt of early special education/special education services, further examination will determine whether children or adolescents participated in speech-language therapy services through the school system. Access to these services may have occurred at any time. Participating in an evaluation (but not yet receiving access to services) is not counted as "reported participation in services" here.*
    - 0 = no reported participation
    - 1 = yes reported participation
    - NA = not applicable (if no reported receipt of early special education/special education services)
- If reported receipt of early special education/special education services – reported participation in occupational therapy services through school system (School-Based Occupational Therapy)
    - *Definition: Following review of information related to potential receipt of early special education/special education services, further examination will determine whether children or adolescents participated in occupational therapy services through the school system. Access to these services may have occurred at any time. Participating in an evaluation (but not yet receiving access to services) is not counted as "reported participation in services" here.*
    - 0 = no reported participation
    - 1 = yes reported participation

    - NA = not applicable (if no reported receipt of early special education/special education services)
- If reported receipt of early special education/special education services – reported participation in physical therapy services through school system (School-Based Physical Therapy)
    - *Definition: Following review of information related to potential receipt of early special education/special education services, further examination will determine whether children or adolescents participated in physical therapy services through the school system. Access to these services may have occurred at any time. Participating in an evaluation (but not yet receiving access to services) is not counted as "reported participation in services" here.*
    - 0 = no reported participation
    - 1 = yes reported participation
    - NA = not applicable (if no reported receipt of early special education/special education services)
- If reported receipt of early special education/special education services – reported participation in psychological intervention services through school system (School-Based Psych Intervention)
    - *Definition: Following review of information related to potential receipt of early special education/special education services, further examination will determine whether children or adolescents participated in psychological intervention services through the school system. Access to these services may have occurred at any time, and potential services may include cognitive behavioral intervention, applied behavior analysis treatment, behavioral intervention and supports, or counseling intervention. Participating in an evaluation (but not yet receiving access to services) is not counted as "reported participation in services" here.*
    - 0 = no reported participation
    - 1 = yes reported participation
    - NA = not applicable (if no reported receipt of early special education/special education services)
- If disorder-specific screening measure for ASD reported by referring healthcare provider – overall risk status indicated (Overall ASD Screening Risk Status)
    - *Definition: Following determination of the overall score that the infant or child achieved on the reported ASD disorder-specific screening measure, the electronic health record will be examined to determine the overall risk status indicated for the reported screening measure.*
    - 0 = risk for ASD not reported
    - 1 = low risk for ASD
    - 2 = moderate risk for ASD
    - 3 = high risk for ASD
    - NA = not applicable (disorder-specific screening measure not reported in record)

- Match of referral and associated diagnosis (Match of Referral and Associated Diagnosis)
    - *Definition: Information from electronic health records will be reviewed to determine the match between the indicated referral concern and subsequent diagnosis assigned for infants, children, and adolescents seen by clinicians in the A&DD Clinic. Indicated referral concerns by referring healthcare providers may include ASD, ID, or DD. Subsequent diagnoses assigned may include ASD, ID, global developmental delay, speech-language disorder, genetic disorder, ADHD, anxiety disorder/obsessive compulsive disorder/adjustment disorder, or mood disorder. Because this study is concerned with understanding the pathway towards referral for ASD and subsequent diagnosis of ASD, outlined variables will be situated within this frame of reference.*
    - Special Note: If no subsequent diagnosis of ASD was made, it will be specifically recorded whether that individual received a diagnosis of another disorder (and what the disorder was) or did not receive a diagnosis at all. For any situations in which an individual received a diagnosis of ASD and a diagnosis of another disorder (ID, ADHD, etc.), this will be recorded as a subsequent diagnosis of ASD. This factor is the dependent variable for Research Question #1. See "variable" included below for all potential options of what "no subsequent diagnosis of ASD" could include.
    - 0 = Referral for ASD and subsequent diagnosis of ASD
    - 1 = Referral for another disorder and subsequent diagnosis of ASD
    - 2 = Referral for ASD and no subsequent diagnosis of ASD
    - 3 = Referral for another disorder and no subsequent diagnosis of ASD
- Alternative match of referral and associated diagnosis (New Match of Referral and Associated Diagnosis)
    - *Definition: Information from electronic health records was reviewed to determine the match between the indicated referral concern and subsequent diagnosis assigned for infants, children, and adolescents seen by clinicians in the A&DD Clinic. Again, indicated referral concerns by referring healthcare providers may have included ASD, ID, or DD, and subsequent diagnoses assigned may have included ASD, ID, global developmental delay, speech-language disorder, genetic disorder/difference, ADHD, anxiety, obsessive compulsive, or adjustment disorder, or mood disorder. This variable was created to assist with running planned statistical analyses, as two of the "Match of Referral and Associated Diagnosis" classifications included above (specifically "1 = referral for another disorder and subsequent diagnosis of ASD" and "2 = referral for ASD and no subsequent diagnosis of ASD") often did not have a sufficient number of cases within each predetermined variable level. As previously mentioned, because this study was concerned with understanding the pathway towards referral for ASD and subsequent diagnosis of ASD, outlined variables were situated within this frame of reference.*

    - 0 = Match (referral for ASD and subsequent diagnosis of ASD)
    - 1 = Unmatched (referral for another disorder and subsequent diagnosis of ASD OR referral for ASD and no subsequent diagnosis of ASD)
    - 2 = Other (referral for another disorder and no subsequent diagnosis of ASD)
- No subsequent diagnosis of ASD (No Subsequent Diagnosis of ASD Information)
    - *Definition: If no subsequent diagnosis of ASD was made for the previous dependent variable ("match of referral and associated diagnosis"), it will be specifically recorded whether that individual received a diagnosis of another disorder (and what the disorder was), received more than one other disorder diagnoses (and what those disorders were), or did not receive a diagnosis at all.*
    - NA = not applicable (if the child did receive a subsequent diagnosis of ASD)
    - 1 = no new diagnosis received
    - 2 = diagnosis of ID
    - 3 = diagnosis of GDD
    - 4 = diagnosis of speech-language disorder
    - 5 = diagnosis of genetic disorder/difference
    - 6 = diagnosis of ADHD
    - 7 = diagnosis of anxiety disorder/obsessive compulsive disorder/adjustment disorder
    - 8 = diagnosis of mood disorder
    - 9 = diagnosis of ID and speech-language disorder
    - 10 = diagnosis of ADHD and speech-language disorder
    - 11 = diagnosis of ADHD and GDD
    - 12 = diagnosis of GDD and speech-language disorder
    - 13 = diagnosis of mood disorder and speech-language disorder
    - 14 = diagnosis of anxiety disorder/obsessive compulsive disorder/adjustment disorder and speech-language disorder
- Timeliness of referral to the clinic (Timeliness of Clinic Referral)
    - *Definition: Information from electronic health records will be examined to determine the timeliness of referral from referring healthcare providers for infants, children, and adolescents seen in the A&DD Clinic. Because this study is concerned with understanding the timeliness of referral in terms of referral for children at or before three years of age compared to referral for children after three years of age, outlined variables will be situated within this frame of reference. Children referred under or up to three years and eleven months of age (47 months) will be considered as a "timely referral to the clinic."*
    - Special Note: This factor is the dependent variable for Research Question #2.
    - 0 = Referral at or before individual is three years of age
    - 1 = Referral after individual is three years of age

Family-Related Factors:

- Caregiver-reported age of initial concern (Caregiver-Reported Age of Concern)
    - *Definition: Information from electronic health records will be reviewed to determine the initial age at which caregivers reportedly became concerned about their infant, child, or adolescent's development.*
    - NA = not reported
    - Year and month of age – converted into total months of age
- Specific caregiver-reported behavior of initial concern (Specific Initial Behavior of Concern)
    - *Definition: Information from electronic health records will be searched to determine the initial behavior which reportedly raised concerns for caregivers regarding their infant, child, or adolescent's development. Some potential behaviors of initial concern may include delays or differences in speech/language skills; language regression; delays or differences in motor skills; delays or differences across global development; global developmental regression; odd communication skills; lack of social interaction; lack of eye contact; restrictive and repetitive behaviors; challenging behaviors; medical complications; or more than one initial concern reported.*
    - NA = not applicable (behavior of initial concern not reported in electronic health record)
    - 1 = delays or differences in speech/language skills
    - 2 = language regression
    - 3 = delays or differences in motor skills (fine/gross)
    - 4 = delays or differences across global development
    - 5 = global developmental regression
    - 6 = odd social communication skills (response to name, reciprocal conversation skills)
    - 7 = lack of social interaction (play skills, engagement with others)
    - 8 = lack of eye contact
    - 9 = restrictive and repetitive behaviors (sensory differences, intense interests/preferences)
    - 10 = challenging behaviors (overactivity, fear of others, frequent crying, tantrums, physical aggression)
    - 11 = medical complications (feeding, sleeping, memory concerns)
    - 12 = more than one initial concern (delays in speech/language and delays in motor skills, delays in speech/language and challenging behaviors, delays in speech/language and odd social communication skills, global developmental regression and challenging behaviors, delays in motor skills and challenges with feeding)
- General caregiver-reported behavior of initial concern (General Initial Behavior of Concern)

    - *Definition: Information from electronic health records will be searched to determine the initial behavior which reportedly raised concerns for caregivers regarding their infant, child, or adolescent's development. Some potential behaviors of initial concern may include delays, differences, or regression in speech/language skills; delays, differences, or regression in motor skills or global developmental skills; social communication differences; restrictive and repetitive behaviors; challenging behaviors; medical complications; or more than one initial concern reported.*
    - NA = not applicable (behavior of initial concern not reported in electronic health record)
    - 1 = delays, differences, or regression in speech/language skills (combining 1 and 2 above)
    - 2 = delays, differences, or regression in motor skills or global developmental skills (combining 3, 4, and 5 above)
    - 3 = social communication differences (combining 6, 7, and 8 above)
    - 4 = restrictive and repetitive behaviors (9 above)
    - 5 = challenging behaviors (10 above)
    - 6 = medical complications (11 above)
    - 7 = more than one initial concern (12 above)
- General caregiver-reported behavior of initial concern and ASD ever (General Initial Behavior of Concern, Ever ASD)
    - *Interaction variable*
    - NA = not applicable (behavior of initial concern not reported in electronic health record)
    - 1 = delays, differences, or regression in speech/language skills (combining 1 and 2 above), no ASD ever
    - 2 = delays, differences, or regression in speech/language skills (combining 1 and 2 above), yes ASD ever
    - 3 = delays, differences, or regression in motor skills or global developmental skills (combining 3, 4, and 5 above), no ASD ever
    - 4 = delays, differences, or regression in motor skills or global developmental skills (combining 3, 4, and 5 above), yes ASD ever
    - 5= social communication differences (combining 6, 7, and 8 above), no ASD ever
    - 6 = social communication differences (combining 6, 7, and 8 above), yes ASD ever
    - 7 = restrictive and repetitive behaviors (9 above), no ASD ever
    - 8 = restrictive and repetitive behaviors (9 above), yes ASD ever
    - 9 = challenging behaviors (10 above), no ASD ever
    - 10 = challenging behaviors (10 above), yes ASD ever
    - 11 = medical complications (11 above), no ASD ever
    - 12 = medical complications (11 above), yes ASD ever

    - 13 = more than one initial concern (12 above), no ASD ever
    - 14 = more than one initial concern (12 above), yes ASD ever
- Family insurance type (Family Insurance Type)
    - *Definition: Information recorded in electronic health records will be reviewed to determine the insurance type of families receiving diagnostic services from clinicians in the A&DD Clinic. Public health insurance can include Medicaid Wisconsin, Medicaid Illinois, Mercycare Medicaid, BadgerCare Plus, Quartz BadgerCare, TRICARE/Champus, Meridian Health, and Meridian Health Plan. Private health insurance can include Anthem Blue Cross Blue Shield, Blue Cross Blue Shield of Illinois, United Healthcare, UMR United Healthcare, Aetna, Humana, Alliance Humana, Quartz Community Network, Quartz University of Wisconsin Health, Quartz One, Quartz, Quartz Unity, Molina Healthcare, Auxiant, Alliance Auxiant, Managed Health Services, Medical Associates, Health Partners, WEA Insurance Trust, Community Care Program for Financial Assistance, Security Health Plan, Alliance Professional Benefit, Dean Health Plan, Deancare, Mercycare, Unity Health Plan, Cigna, Cigna Open Access, Group Health Cooperative Health Plan, Network Health Plan, WPS Health Plan, and Aspirus Arise Health Plan.*
    - 0 = Public health insurance
    - 1 = Private health insurance
- Family insurance type and ASD ever (Family Insurance Type, Ever ASD)
    - *Interaction variable*
    - 0 = Public health insurance, no ASD ever
    - 1 = Public health insurance, yes ASD ever
    - 2 = Private health insurance, no ASD ever
    - 3 = Private health insurance, yes ASD ever
- Household zip code (Household Zip Code)
    - *Definition: Information from electronic health records will be examined to determine the household zip code of families at the time of referral and diagnosis. This factor will serve as a proxy for geographic location. Household zip codes will be fully written out and will be grouped and coded based on similarity in health service areas (related to healthcare services and surrounding municipalities) identified through the Wisconsin Area Health Education Centers service area groupings. These may include metro health service areas, urban health service areas, mixed health service areas, rural health service areas, or out of state (for any families living outside the state of Wisconsin).*
    - 0 = metro health service area
    - 1 = urban health service area
    - 2 = mixed health service area
    - 3 = rural health service area
    - 4 = out of state

- Household zip code and ASD ever (Household Zip Code, Ever ASD)
    - *Interaction variable*
    - 0 = metro health service area, no ASD ever
    - 1 = metro health service area, yes ASD ever
    - 2 = urban health service area, no ASD ever
    - 3 = urban health service area, yes ASD ever
    - 4 = mixed health service area, no ASD ever
    - 5 = mixed health service area, yes ASD ever
    - 6 = rural health service area, no ASD ever
    - 7 = rural health service area, yes ASD ever
    - 8 = out of state, no ASD ever
    - 9 = out of state, yes ASD ever

Referring Healthcare Provider-Related Factors:

- Screening measure type reported by referring healthcare provider (Screening Measure Type by RHCP)
    - *Definition: Information from electronic health records will be reviewed to determine if screening was reported by the referring healthcare provider prior to referral of infants and children to the A&DD Clinic. Types of screening may include no reported use of tools, developmental screening tools, disorder-specific tools for ASD, or both developmental screening tools and disorder-specific tools for ASD.*
    - NA = no screening measure reported
    - 1 = only developmental screening measure reported
    - 2 = only disorder-specific screening measure for ASD reported
    - 3 = both developmental screening measure and disorder-specific screening measure reported
- Screening measure reported by referring healthcare provider and ASD ever (Screening Measure Type, Ever ASD)
    - *Interaction variable*
    - 0 = no screening measure reported, no ASD ever
    - 1 = no screening measure reported, yes ASD ever
    - 2 = some type of screening measure reported, no ASD ever
    - 3 = some type of screening measure reported, yes ASD ever
- If developmental screening measure reported – name of screening tool (Name of Developmental Screening Tool)
    - *Definition: Following review of information related to the type of screening measures used, electronic health records will be examined to determine the developmental screening tool reported for the referred infant or child. Developmental screening tools can include the Ages and Stages Questionnaire,*

Third Edition (ASQ-3) or the Developmental Assessment of Young Children, Second Edition (DAYC-2).
    - NA = not applicable/screening name not reported (developmental screening measure not reported)
    - 1 = Ages and Stages Questionnaire, Third Edition (ASQ-3)
    - 2 = Developmental Assessment of Young Children, Second Edition (DAYC-2)
- If disorder-specific screening measure reported – name of screening tool (Name of ASD Screening Tool)
    - *Definition: Following review of information related to type of screening measures used, electronic health records will be examined to determine the ASD disorder-specific screening tool reported for the referred infant or child. ASD disorder-specific screening tools can include the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F).*
    - NA = not applicable/screening name not reported (disorder-specific screening measure not reported)
    - 1 = Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)
- Practice type of referring healthcare provider (RHCP Practice Type)
    - *Definition: Information from electronic health records will be reviewed to determine the specific practice type in which referring healthcare providers work. Setting types may include pediatric primary care practice, family medicine primary care practice, or pediatric specialty practice (including developmental pediatrics, psychiatry, rehabilitation medicine, neurology, complex care, genetics, infectious disease, otolaryngology, neurological surgery, endocrinology, or metabolic disorders).*
    - NA = practice type not reported
    - 1 = primary care pediatric practice type
    - 2 = primary care family medicine practice type
    - 3 = specialty care pediatrics practice type
- Practice type of referring healthcare provider and ASD ever (RHCP Practice Type, Ever ASD)
    - *Interaction variable*
    - 0 = primary care pediatric practice type, no ASD ever
    - 1 = primary care pediatric practice type, yes ASD ever
    - 2 = primary care family medicine practice type, no ASD ever
    - 3 = primary care family medicine practice type, yes ASD ever
    - 4 = specialty care pediatric practice type, no ASD ever
    - 5 = specialty care pediatric practice type, yes ASD ever
- Clinical practice zip code of referring healthcare provider (RHCP Practice Zip Code)
    - *Definition: Information from electronic health records will be examined to determine the clinical practice zip code of referring healthcare providers at the*

time of referral to the A&DD Clinic. This factor will serve as a proxy for geographic/regional location. Clinical practice zip codes will be fully written out and will be grouped and coded based on similarity in health service areas (related to healthcare services and surrounding municipalities) identified through the Wisconsin Area Health Education Center (AHEC) service area groupings. These may include metro health service areas, urban health service areas, mixed health service areas, rural health service areas, or out of state (for any referring healthcare providers working outside the state of Wisconsin).

  - 0 = metro health service area
  - 1 = urban health service area
  - 2 = mixed health service area
  - 3 = rural health service area
  - 4 = out of state
- Clinical practice zip code of referring healthcare provider and ASD ever (Practice Zip Code, Ever ASD)
  - *Interaction variable*
  - 0 = metro health service area, no ASD ever
  - 1 = metro health service area, yes ASD ever
  - 2 = urban health service area, no ASD ever
  - 3 = urban health service area, yes ASD ever
  - 4 = mixed health service area, no ASD ever
  - 5 = mixed health service area, yes ASD ever
  - 6 = rural health service area, no ASD ever
  - 7 = rural health service area, yes ASD ever
  - 8 = out of state, no ASD ever
  - 9 = out of state, yes ASD ever
- Professional role type of referring healthcare provider (RHCP Role Type)
  - *Definition: Information from electronic health records will be reviewed to determine the specific professional role type of the referring healthcare providers. Professional role types may include being a Doctor of Medicine (MD) provider, a Doctor of Osteopathy (DO) provider, a Nurse Practitioner (NP) provider, or a Physician Assistant (PA) provider.*
  - 0 = Doctor of Medicine (MD) provider
  - 1 = Doctor of Osteopathy (DO) provider
  - 2 = Nurse Practitioner (NP) provider
  - 3 = Physician Assistant (PA) provider
- Professional role type of referring healthcare provider and ASD ever (RHCP Role Type, Ever ASD)
  - *Interaction variable*
  - 0 = MD provider, no ASD ever
  - 1 = MD provider, yes ASD ever

    - 2 = DO provider, no ASD ever
    - 3 = DO provider, yes ASD ever
    - 4 = NP provider, no ASD ever
    - 5 = NP provider, yes ASD ever
    - 6 = PA provider, no ASD ever
    - 7 = PA provider, yes ASD ever
- Chief concern listed on referral form by referring healthcare provider (RHCP Chief Concern)
    - *Definition: Information from electronic health records will be examined to determine the chief concern listed on the referral form submitted to the A&DD Clinic by the referring healthcare provider. Chief referral concerns may include ASD, ID, or DD (which includes speech-language delay, motor delay, and/or global developmental delay).*
    - 0 = ASD chief concern
    - 1 = ID chief concern
    - 2 = DD chief concern

Appendix 3

Cell by Cell Comparisons for Chi-Square Tests of Independence – Research Question #1

Child-Related Factors:

Contingency Table 1 –

Biological Sex of Child x Match of Referral and Subsequent Diagnosis

	Male Sex	Female Sex
Referral for ASD; Diagnosis of ASD	Observed: 157 Expected: 146.98	Observed: 48 Expected: 58.01
Referral for Another Disorder; Diagnosis of ASD	Observed: 25 Expected: 22.94	Observed: 7 Expected: 9.05
Referral for ASD; No Diagnosis of ASD	Observed: 44 Expected: 48.75	Observed: 24 Expected: 19.25
Referral for Another Disorder; No Diagnosis of ASD	Observed: 40 Expected: 47.32	Observed: 26 Expected: 18.68

Contingency Table 2 –

Ever ID Diagnosis x Alternative Match of Referral and Subsequent Diagnosis

	Never ID Diagnosis	Yes Ever ID Diagnosis
Match: Referral for ASD; Diagnosis of ASD	Observed: 197 Expected: 191.74	Observed: 8 Expected: 13.26
Unmatched: Referral for Another Disorder; Diagnosis of ASD OR Referral for ASD, No Diagnosis of ASD	Observed: 93 Expected: 93.53	Observed: 7 Expected: 6.47
Other: Referral for Another Disorder; No Diagnosis of ASD	Observed: 57 Expected: 61.73	Observed: 9 Expected: 4.27

Contingency Table 3 –

Current GDD Diagnosis x Alternative Match of Referral and Subsequent Diagnosis

	No Current GDD Diagnosis	Yes Current GDD Diagnosis
Match: Referral for ASD; Diagnosis of ASD	Observed: 193 Expected: 183.45	Observed: 12 Expected: 21.55
Unmatched: Referral for Another Disorder; Diagnosis of ASD OR Referral for ASD, No Diagnosis of ASD	Observed: 85 Expected: 89.49	Observed: 15 Expected: 10.51
Other: Referral for Another Disorder; No Diagnosis of ASD	Observed: 54 Expected: 59.06	Observed: 12 Expected: 6.94

Contingency Table 4 –

Ever Genetic Disorder/Difference Diagnosis x Alternative Match of Referral and Subsequent Diagnosis

	Never Genetic Diagnosis	Yes Ever Genetic Diagnosis
Match: Referral for ASD; Diagnosis of ASD	Observed: 184 Expected: 182.35	Observed: 21 Expected: 22.65
Unmatched: Referral for Another Disorder; Diagnosis of ASD OR Referral for ASD, No Diagnosis of ASD	Observed: 93 Expected: 88.95	Observed: 7 Expected: 11.05
Other: Referral for Another Disorder; No Diagnosis of ASD	Observed: 53 Expected: 58.71	Observed: 13 Expected: 7.29

Referring Healthcare Provider-Related Factors:

Contingency Table 5 –

Provider Practice Type x Alternative Match of Referral and Subsequent Diagnosis

	Pediatric Primary Care	Family Medicine Primary Care	Pediatric Specialty Care
Match: Referral for ASD; Diagnosis of ASD	Observed: 123 Expected:118.01	Observed: 63 Expected: 62.61	Observed: 19 Expected: 24.38
Unmatched: Referral for Another Disorder; Diagnosis of ASD OR Referral for ASD, No Diagnosis of ASD	Observed: 57 Expected: 56.99	Observed: 34 Expected: 30.23	Observed: 8 Expected: 11.77
Other: Referral for Another Disorder; No Diagnosis of ASD	Observed: 33 Expected: 37.99	Observed: 16 Expected: 20.16	Observed: 17 Expected: 7.85

Appendix 4

Cell by Cell Comparisons for Chi-Square Tests of Independence – Research Question #2

Child-Related Factors:

Contingency Table 1 –

Previous ASD Diagnosis x Timeliness of Referral to Diagnostic Clinic

	No Previous ASD Diagnosis	Yes Previous ASD Diagnosis
Timely Referral to Clinic (Before or At Three)	Observed: 183 Expected: 175.66	Observed: 7 Expected: 14.34
Untimely Referral to Clinic (After Three)	Observed: 160 Expected: 167.34	Observed: 21 Expected: 13.66

Contingency Table 2 –

Current GDD Diagnosis x Timeliness of Referral to Diagnostic Clinic

	No Current GDD Diagnosis	Yes Current GDD Diagnosis
Timely Referral to Clinic (Before or At Three)	Observed: 158 Expected: 170.03	Observed: 32 Expected: 19.97
Untimely Referral to Clinic (After Three)	Observed: 174 Expected: 161.97	Observed: 7 Expected: 19.03

Contingency Table 3 –

Current Speech-Language Diagnosis x Timeliness of Referral to Diagnostic Clinic

	No Current SL Diagnosis	Yes Current SL Diagnosis
Timely Referral to Clinic (Before or At Three)	Observed: 112 Expected: 129.06	Observed: 78 Expected: 60.94
Untimely Referral to Clinic (After Three)	Observed: 140 Expected: 122.94	Observed: 41 Expected: 58.06

Contingency Table 4 –

Early Intervention Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Reported Enrollment	Yes Reported Enrollment
Timely Referral to Clinic (Before or At Three)	Observed: 60 Expected: 91.67	Observed: 130 Expected: 98.33
Untimely Referral to Clinic (After Three)	Observed: 119 Expected: 87.33	Observed: 62 Expected: 93.67

Contingency Table 5 –

Early Childcare Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Reported Enrollment	Yes Reported Enrollment
Timely Referral to Clinic (Before or At Three)	Observed: 151 Expected: 161.32	Observed: 39 Expected: 28.68
Untimely Referral to Clinic (After Three)	Observed: 164 Expected: 153.68	Observed: 17 Expected: 27.32

Contingency Table 6 –

Speech-Language Therapy Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Reported Enrollment	Yes Reported Enrollment
Timely Referral to Clinic (Before or At Three)	Observed: 22 Expected: 43.83	Observed: 125 Expected: 103.17
Untimely Referral to Clinic (After Three)	Observed: 60 Expected: 38.17	Observed: 68 Expected: 89.83

Contingency Table 7 –

Psychological Intervention Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Reported Enrollment	Yes Reported Enrollment
Timely Referral to Clinic (Before or At Three)	Observed: 130 Expected: 100.81	Observed: 18 Expected: 47.19
Untimely Referral to Clinic (After Three)	Observed: 58 Expected: 87.19	Observed: 70 Expected: 40.81

Contingency Table 8 –

Special Education/Early Special Education Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Reported Enrollment	Yes Reported Enrollment
Timely Referral to Clinic (Before or At Three)	Observed: 131 Expected: 94.74	Observed: 59 Expected: 92.26
Untimely Referral to Clinic (After Three)	Observed: 54 Expected: 90.26	Observed: 127 Expected: 90.74

Contingency Table 9 –

Ever ASD/Ever GDD x Timeliness of Referral to Diagnostic Clinic

	No ASD Ever, No GDD Ever	No ASD Ever, Yes GDD Ever	Yes ASD Ever, No GDD Ever	Yes ASD Ever, Yes GDD Ever
Timely Referral to Clinic (Before or at Three)	Observed: 36 Expected: 38.41	Observed: 22 Expected: 16.39	Observed: 105 Expected: 115.23	Observed: 27 Expected: 19.97
Untimely Referral to Clinic (After Three)	Observed: 39 Expected: 36.59	Observed: 10 Expected: 15.61	Observed: 120 Expected: 109.77	Observed: 12 Expected: 19.03

Contingency Table 10 –

Ever ASD/Ever Speech-Language Diagnosis x Timeliness of Referral to Diagnostic Clinic

	No ASD Ever, No SL Ever	No ASD Ever, Yes SL Ever	Yes ASD Ever, No SL Ever	Yes ASD Ever, Yes SL Ever
Timely Referral to Clinic (Before or at Three)	Observed: 29 Expected: 26.63	Observed: 29 Expected: 28.17	Observed: 65 Expected: 80.40	Observed: 67 Expected: 54.79
Untimely Referral to Clinic (After Three)	Observed: 23 Expected:25.37	Observed: 26 Expected: 26.83	Observed: 92 Expected: 76.59	Observed: 40 Expected: 52.20

Contingency Table 11 –

Ever ASD/Early Intervention Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Enrollment, No ASD Ever	No Enrollment, Yes ASD Ever	Yes Enrollment, No ASD Ever	Yes Enrollment, Yes ASD Ever
Timely Referral to Clinic (Before or at Three)	Observed: 20 Expected: 25.61	Observed: 40 Expected: 66.06	Observed: 37 Expected: 29.19	Observed: 93 Expected: 69.14
Untimely Referral to Clinic (After Three)	Observed: 30 Expected: 24.39	Observed: 89 Expected: 62.94	Observed: 20 Expected: 27.81	Observed: 42 Expected: 65.86

Contingency Table 12 –

Ever ASD/Early Childcare Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Enrollment, No ASD Ever	No Enrollment, Yes ASD Ever	Yes Enrollment, No ASD Ever	Yes Enrollment, Yes ASD Ever
Timely Referral to Clinic (Before or at Three)	Observed: 43 Expected: 45.07	Observed: 108 Expected: 116.25	Observed: 14 Expected: 9.73	Observed: 25 Expected: 18.95
Untimely Referral to Clinic (After Three)	Observed: 45 Expected: 42.93	Observed: 119 Expected: 110.75	Observed: 5 Expected: 9.27	Observed: 12 Expected: 18.05

Contingency Table 13 –

Ever ASD/Speech-Language Therapy Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Enrollment, No ASD Ever	No Enrollment, Yes ASD Ever	Yes Enrollment, No ASD Ever	Yes Enrollment, Yes ASD Ever
Timely Referral to Clinic (Before or at Three)	Observed: 7 Expected: 10.72	Observed: 16 Expected: 33.78	Observed: 37 Expected: 31.64	Observed: 88 Expected: 71.86
Untimely Referral to Clinic (After Three)	Observed: 13 Expected: 9.28	Observed: 47 Expected: 29.22	Observed: 22 Expected: 27.36	Observed: 46 Expected: 62.14

Contingency Table 14 –

Ever ASD/Psychological Intervention Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Enrollment, No ASD Ever	No Enrollment, Yes ASD Ever	Yes Enrollment, No ASD Ever	Yes Enrollment, Yes ASD Ever
Timely Referral to Clinic (Before or at Three)	Observed: 37 Expected: 30.57	Observed: 93 Expected: 70.25	Observed: 8 Expected: 12.33	Observed: 10 Expected: 34.86
Untimely Referral to Clinic (After Three)	Observed: 20 Expected: 26.43	Observed: 38 Expected: 60.75	Observed: 15 Expected: 10.67	Observed: 55 Expected: 30.14

Contingency Table 15 –

Ever ASD/Special Education/Early Special Education Enrollment x Timeliness of Referral to Diagnostic Clinic

	No Enrollment, No ASD Ever	No Enrollment, Yes ASD Ever	Yes Enrollment, No ASD Ever	Yes Enrollment, Yes ASD Ever
Timely Referral to Clinic (Before or at Three)	Observed: 35 Expected: 24.58	Observed: 96 Expected: 70.16	Observed: 20 Expected: 28.68	Observed: 39 Expected: 66.58
Untimely Referral to	Observed: 13 Expected: 23.42	Observed: 41 Expected: 66.84	Observed: 36 Expected: 27.32	Observed: 91 Expected: 63.42

Clinic (After Three)				

Referring Healthcare Provider-Related Factors:

Contingency Table 16 –

Provider Practice Type x Timeliness of Referral to Diagnostic Clinic

	Pediatric Primary Care	Family Medicine Primary Care	Pediatric Specialty Care
Timely Referral to Clinic (Before or at Three)	Observed: 116 Expected: 108.80	Observed: 58 Expected: 57.72	Observed: 15 Expected: 22.48
Untimely Referral to Clinic (After Three)	Observed: 97 Expected: 104.19	Observed: 55 Expected: 55.28	Observed: 29 Expected: 21.52

Contingency Table 17 –

Provider Role Type x Timeliness of Referral to Diagnostic Clinic

	MD Provider	DO Provider	NP Provider	PA Provider
Timely Referral to Clinic (Before or at Three)	Observed: 147 Expected: 155.69	Observed: 19 Expected: 12.80	Observed: 16 Expected: 13.83	Observed: 8 Expected: 7.68
Untimely Referral to Clinic (After Three)	Observed: 157 Expected: 148.31	Observed: 6 Expected: 12.20	Observed: 11 Expected: 13.17	Observed: 7 Expected: 7.32