

From Clinic to Classroom: Investigating IEPs and Diagnostic Clinical Evaluation
Recommendations for Students with a Fetal Alcohol Spectrum Disorder Diagnosis

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Abstract

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Fetal Alcohol Spectrum Disorder (FASD) is associated with neurodevelopmental, cognitive, behavioral, and adaptive impairments that affect educational functioning and access to special education services. Despite increasing recognition of FASD, students on the fetal alcohol spectrum remain under-identified in school settings, and little is known about the extent to which clinical diagnostic recommendations align with school-based educational supports. This study compared interdisciplinary clinical diagnostic reports and school-based Individualized Education Programs (IEPs) for children diagnosed with FASD to examine patterns of alignment and mismatch in eligibility determinations, services, and educational recommendations. Results indicated that 51% of participants had a preexisting IEP at the time of diagnosis, with moderate overall agreement between clinic recommendations and school-based eligibility determinations.

However, discrepancies were frequently observed in the extent to which IEPs addressed students' documented neurodevelopmental and functional needs, particularly among students with greater central nervous system impairment and in areas related to occupational therapy and transition planning. Findings suggest that educational identification and service provision may be more strongly associated with observable functional impairment than with categorical FASD diagnoses alone. Implications highlight the importance of interdisciplinary collaboration and the role of school psychologists in translating clinical evaluation findings into educationally relevant supports and interventions for students on the fetal alcohol spectrum.

Keywords: Fetal Alcohol Spectrum Disorder, prenatal alcohol exposure, individualized education programs, special education eligibility, school psychology

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Chapter One: Introduction

Decades of research demonstrate the broad behavioral and cognitive effects of prenatal exposure to alcohol (Glass et al., 2014; Astley, 2013). The prevalence rate of Fetal Alcohol Spectrum Disorders (FASD) is estimated to be between 2-7% of children in the United States, though many studies highlight that FASD research remains despairingly under-resourced, is a disability that is widely misunderstood, and may be the most stigmatized of all neurodevelopmental disabilities in the United States (Choate & Badry, 2019; May et al., 2021; Millar et al., 2017). The current prevalence estimates of FASD – often referred to as a ‘hidden’ disability because this disability manifests so variably across the spectrum – suggest that schools likely have more students with FASDs than are realized (Blackburn, Carpenter & Egerton, 2012; Boys et al., 2016; Millar et al., 2017). Caregiver-reported experiences of the public school system point to a general lack of understanding of FASD from educators and other educational professionals who do not recognize FASD for the brain-based disability that it is (Choate & Badry, 2019; Reedman, Breen & Wu, 2024). Thus, children with an FASD diagnosis face complex challenges that may surpass the scope of standard supports that are provided through special education programs in the United States (Skorka et al., 2020). Although Individualized Education Plans (IEPs) are designed to address the specific needs of all students with qualifying disabilities, the cognitive and functional impacts and needs associated with FASD may be inadequately addressed and supported by current evaluation and intervention practices in schools (Kurth et al., 2022; Mattson, Bernes & Doyle, 2019; Millar et al., 2017).

Developmental Impacts Across the FASD Spectrum

The neurobehavioral and neurocognitive functioning of children with a diagnosis of FASD has been studied extensively (Carr, Agnihotri & Keightley, 2010). Alcohol is a known

teratogen, or substance that presents a “major commission risk to the developing fetal brain” (Georgieff, Tran & Carlson, 2018, p. 1065). The impairments associated with the teratogenic impact of prenatal exposure to alcohol can include deficits in cognition and learning, communication, sensory, motor, and executive functions, as well as problems with social-emotional, behavioral, and adaptive skills (Jirikowic, Kartin & Olson, 2008). These challenges impact a child’s daily functioning across settings at home, in school, and in the community and require tailored interventions, accommodations, and strategies to address individual needs (Jirikowic, Kartin & Olson, 2008; Paley & O’Connor, 2011). There is demonstrated variability in the spectrum of an FASD diagnosis – meaning that ‘best approaches to learning’ may differ on an individual basis depending upon the different brain domains that are impacted for the child (Millar et al., 2017). The clinical complexities of FASD simultaneously demonstrate the multifaceted needs of students with FASD and emphasize the importance of individualized and comprehensive needs-driven services and accommodations and support for this population (Pei et al., 2021).

Legal Precedent for Special Education Services in Public Schools

After the passing of the Education for All Handicapped Children Act (1975), several landmark cases collectively reinforced the power of caregiver advocacy in ensuring students with disabilities have equal access to free and appropriate public education and receive necessary support to fully receive the benefits of public education. Among these court decisions include *Mills v. Board of Education of District of Columbia* (1972), which established that students who have disabilities ranging from physical, mental, and emotional, are entitled to and must be provided public education; *Board of Education v. Rowley* (1982), establishing a two-part test that courts must use in order to determine whether a school district has indeed provided free and

appropriate public education to a child who has an IEP; and *Doug C. v. Hawaii Department of Education* (2013), legally requiring the participation of at least one caregiver in all steps of the special education process and any meeting held to discuss the child's IEP. Ultimately, the passing of the Education for All Handicapped Children Act – which has since been reauthorized and renamed as the Individuals with Disabilities Education Act (IDEA) – mandated free and appropriate public education (FAPE) in the least restrictive environment (LRE) for all children identified with a disability. As a requirement of IDEA (2004), IEPs provide a legal framework for setting measurable goals and identifying interventions and accommodations for students who with a qualifying disability in schools. When a child has been evaluated and determined to have a disability that adversely impacts their ability to learn in the general education classroom, the child is deemed eligible for special education services and an IEP.

Disability Category Eligibility

Through federal law, public schools are mandated to develop IEPs for all children who are determined to have a disability that adversely impacts the child's ability to learn from the general education curriculum (U.S. Department of Education, 2018). The 13 disabilities currently recognized by the U.S. Department of Education are: autism spectrum disorder (ASD), Deaf-Blindness, Deafness, Emotional Behavior Disturbance (EBD), Hearing Impairment, Intellectual Disability, Multiple Disabilities, Orthopedic Impairment, Other Health Impairment (OHI), Specific Learning Disability (SLD), Speech or Language Impairment, Traumatic Brain Injury (TBI), and Visual Impairment. Thus, a child with any of these disabilities whose disability has a negative impact on their learning from the general education curriculum is eligible for special education services and an IEP. Under IDEA, the eligibility category "Multiple Disabilities" is used when a student has two or more co-occurring impairments, and the combined impact of

these disabilities creates significant educational needs that cannot be met through special education services designed to address only one disability (U.S. Department of Education, 2018). This category does not include students with deaf-blindness, as this is classified as its own category under IDEA. FASD is not recognized by the IDEA (2004) as a disability category that can qualify a child for special education services in the United States (Petrenko et al., 2014). For children with FASDs, the relationship between their diagnosis and their specific educational and social/emotional and behavioral impairments are often not straightforward and are highly individual.

Stigma as a Pervasive Barrier in the Field of FASD Research and Diagnosis

Stigma surrounding FASD is a multifaceted issue that impacts diagnosis, prevention, and support for children and their families. As a result, educators may be unaware entirely that a student in their classroom has a diagnosis of FASD, in part due to caregivers' hesitation to share the diagnosis or because the child has not received a formal diagnosis (Choate & Badry, 2019). The social stigma that is attached to a diagnosis of FASD presents a profound barrier to caregiver participation in the education of their child. Link and Phalen (2001) offer a definition of stigma as occurring "when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them" (p. 377).

Bell et al. (2016) discuss stigma as a considerable barrier for caregivers when choosing whether to seek and disclose a formal diagnosis of FASD, reveal alcohol use, and seek and access support. Caregivers of children with FASDs often feel isolated and frustrated with the lack of understanding and support from not just their social networks and healthcare providers, but also their child's educators as well. In their study comparing parental experiences with accessing school support for three prevalent neurodevelopmental disorders, McCarthy et al. (2022)

discovered that parents of children who were diagnosed with autism spectrum disorder (ASD) and/or with Attention Deficit/Hyperactivity Disorder (ADHD) were more likely to name and discuss these more widely known and understood diagnoses than parents of children with an FASD diagnosis. Addressing the stigmatized reality of this disability is increasingly important to remove this barrier for children to access necessary intervention and accommodation support.

Evaluation for Services

When a family does seek services for their child, they must go through a formal process to have their child's disability evaluated by qualified professionals. As previously mentioned, there is significant individual variability of impact with an FASD diagnosis; addressing the needs associated with FASD should include a comprehensive evaluation with multiple informants, sources of data, and professional collaboration (Millar et al., 2017). This research study evaluated and compared outcomes between a school-based multidisciplinary team per a child's preexisting IEP and an interdisciplinary diagnostic clinical team evaluation. The differences between the evaluation processes are noteworthy.

Special Education Evaluation Process

Evaluations in the school setting are conducted in schools using a multidisciplinary team approach, which is comprised of caregivers, general education teachers, special education teachers, school psychologists, related service providers (e.g., occupational therapist, physical therapist), administration, and the student themselves depending on their age and when it is appropriate to include them (U.S. Department of Education, 2018). In multidisciplinary evaluations, school professionals conduct separate, discipline-specific assessments that together produce decisions for special education services in a school (Frey, 2019). A school district has 25 school days to respond to a referral for an evaluation for special education, and once parental

consent is received, the school has 35 school days to evaluate the child, per special education law (Washington Administrative Code § 392-172A-03005 (2025)). If the child is found eligible, the school district has 30 calendar days to create an IEP (Washington Administrative Code § 392-172A-03005 (2025)). The purpose of this evaluation is to both identify strengths and weaknesses in a child's academic and social/emotional and behavioral performances in school. In doing so, the team uses a battery of assessments of the child's functioning across domains to decide if the child has a disability that requires special education services. These determinations are not based on one measurement/assessment but rather a variety of assessments and tools to gather information by appropriately trained professionals.

Clinical Diagnostic Evaluation Process

The evaluation process at a diagnostic clinic for FASD, such as the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network at the University of Washington (UW FAS DPN), differs from school-based evaluations in several ways. First and foremost, the team is interdisciplinary. In contrast to multidisciplinary team evaluations, in which professionals conduct separate assessments which can lead to fragmented interventions and recommendations (Castro-Kemp & Samuels, 2022), interdisciplinary team evaluations integrate diverse expertise through interactive communication and collaboration, which produces higher provider satisfaction and improved follow-up care (Gerdtts et al., 2018). A medical doctor is needed to diagnose the medical components of any diagnosis under the FASD spectrum, for they are needed to assess growth, face, brain structure, neurology and other co-occurring medical conditions. At the UW FAS DPN clinic, the interdisciplinary team includes a developmental pediatrician who diagnoses the child with an FAS diagnosis as determined by domains of functioning determined to be areas of deficit after the evaluation, which is not a role in school-

based multidisciplinary teams. Additionally, an evaluation at this diagnostic clinic takes place over the course of four hours, which includes interviewing the child's caregiver(s), standardized assessment of fine and gross motor, speech/language, and cognitive and academic domains, in addition to questionnaires completed by the caregiver, assessment scoring and interpretation, report writing, recommendations for interventions and accommodations, and feedback to the family. This is much quicker in comparison to school-based evaluation timelines, though diagnostic clinics can have up to 6-months or longer waitlists for an evaluation (Petrenko et al., 2014).

Present Study and Intended Contributions

Given that some children with FASD do not have a formal diagnosis or do not disclose this diagnosis to their teachers, it is unknown how many children may be lacking special education services despite a clear need for support. Research demonstrates the complex learning difficulties and array of neurobehavioral and developmental challenges associated with FASDs, necessitating the development and maintenance of effective IEPs (Khoury & Milligan, 2019; Millar et al., 2017). However, given that many symptoms of FASD overlap with more commonly diagnosed and recognized disorders, such as ADHD and ASD, children who receive a clinical diagnostic evaluation may already have an IEP based on eligibility for symptoms that may have been explained by ADHD, for example. Thus, there is an opportunity in the database available at the UW FAS DPN clinic to determine what eligibility categories are most commonly represented for patients who receive an evaluation.

For the patients who do have an existing IEP but do not have an FASD diagnosis, the interventions and accommodations will reflect the impact of the disability in which the child qualified for special education services; these interventions and accommodations may not fully

capture the complexity and specific individualized needs that come to light with a child's diagnosis of FASD. Considering the differences in the evaluative process between school-based and interdisciplinary clinic-based teams, this study compared the interventions and accommodations identified in a child's IEP with the recommendations from the clinical team in the child's diagnostic report to evaluate whether these recommendations align or differ. Further, examining the potential relationships between demographics and whether or not a patient has a preexisting IEP at the time of the diagnostic evaluation at the UW FAS DPN may expose further barriers to accessing services for specific groups within this population.

Because of underdiagnosis, the exact prevalence rate of FASD in the United States is unknown (CDC, 2024). An aim of this study is to contribute to the field of school psychology which intends to apply expertise in mental health, learning, and behavior to help students succeed academically, socially, behaviorally, and emotionally (NASP, 2020). There are few studies, to the extent that this researcher discovered, that focus on the comparison of interventions and accommodations within IEP and clinical diagnostic reports when a child receives an FASD diagnosis. An additional aim of this study is to contribute to what is known about the unique and complex impact of prenatal exposures on a child's development and educational trajectory while exploring a gap in the comparison of evaluative processes of multidisciplinary and interdisciplinary teams, as well as the alignment of clinical recommendations with preexisting interventions, accommodations, and goals within a child's IEP. The intent of this study was to address these gaps to highlight the impact of comprehensive, individualized, and context-specific educational supports that draw on both diagnostic expertise and practical, in-school implementation for children with FASD. By identifying patterns across cases where clinical insights are—or are not—reflected in IEPs, this study explores whether

interdisciplinary collaboration and evaluation uncover further domains of need and support for a child with an FASD diagnosis that can be integrated into school-based support.

Chapter 2: Literature Review

Fetal Alcohol Spectrum Disorders

Fetal Alcohol Syndrome (FAS) is a disability that results from fetal exposure to alcohol during pregnancy (CDC, 2024). The condition was first identified by Christy Ulleland MD at the University of Washington in 1968 (Ulleland, 1972). She, along with Drs Smith, Jones and Streissguth would coin the term FAS in the medical literature (Jones & Smith, 1973; Jones et al., 1973). The definition has remained relatively constant over the past 50 years. FAS has been broadly characterized by a child's growth deficiency, unique facial anomalies, and structural, neurological and/or functional abnormalities of the individual's brain (Hemingway, 2024). The physical, cognitive, and behavioral deficits and outcomes observed among individuals with prenatal alcohol exposure (PAE) has come to be considered a spectrum of disorders, known as Fetal Alcohol Spectrum Disorders (FASD); FASD, then, is a spectrum of disorders caused by PAE (Hemingway, 2024). Furthermore, FASD serves as an 'umbrella' term that captures a range of diagnoses that vary in severity on each end of the spectrum, with FAS being the most severe diagnosis under this umbrella (Hemingway, 2024).

FASD is not always simple to differentiate from other neurodevelopmental disorders, as many individuals with FASD do not have the unique facial phenotype caused only by PAE; some infants are born with facial abnormalities, though most infants exposed and damaged by PAE are not. The three distinct facial features of FAS are formed during the third week of the first trimester of pregnancy (Sulik, Johnston, & Webb, 1981), and few children who have been prenatally exposed to alcohol will have all three of the required facial features for an FAS diagnosis (Astley 2010; National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2000) . The brain develops throughout fetal gestation, however, which therefore provides a much larger

window of time for the teratogenic effects of alcohol to disrupt the development of the brain (Streissguth & O'Malley, 2000).

Several domains of functioning can be impacted for individuals who are diagnosed on this spectrum, which include impairments in intellectual functioning, information processing, working memory, attention, impulsivity, academic learning, executive functioning, social skills, motor skills, and adaptive functioning (Kodituwakku, 2009; Mattson, Crocker & Nguyen, 2011; Petrenko et al., 2014; Astley 2010). Regarding all levels of FASD, it is estimated that the prevalence of FASD in populations of school-aged children may be as high as 1 to 5 per 100 school-aged children – or 1% to 5% of the population (May et al., 2009; May et al., 2018). The prevalence of FAS in the general population is estimated at 1-3 per 1,000. The prevalence of FAS in high-risk populations like foster care is 1-2 per hundred (Astley et al., 2002). International FASD prevalence rates vary considerably, which is suggested to stem from differences in FASD case definitions and diagnostic methods, as well as geographical and population factors (Brown et al., 2019). Despite this prevalence, fewer resources have been allocated to the study of FASD compared with more widely known and interpreted disorders, such as ADHD and autism (Kodituwakku, 2010). The average lifetime cost of care for one individual with FAS is estimated to be \$2 million, with funds needed for neonatal care in hospitals, developmental disability services including Birth-to-Three, special education, mental health care, and potential supported living – and this average does not include data on individuals with other FASDs (Lupton, Burd & Harwood, 2004; Popova et al., 2011)

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure

In 2013, the American Psychological Association (APA, 2013) introduced Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) was

introduced in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) as a condition for further study intended to capture the neurobehavioral effects of PAE within a psychiatric diagnostic framework. The proposed diagnosis organizes impairments into three domains—neurocognitive functioning, self-regulation, and adaptive functioning—and requires the presence of symptoms across these domains in addition to confirmed prenatal alcohol exposure. However, ND-PAE remains controversial within the FASD field, and its validity as a diagnostic construct continues to be debated. Empirical research evaluating the diagnostic performance of ND-PAE suggests that the criteria may be overly restrictive and may fail to identify many individuals who meet established multidisciplinary diagnostic criteria for FASD.

For example, when ND-PAE criteria were compared with Canadian FASD diagnostic guidelines in a multidisciplinary clinical sample, ND-PAE demonstrated relatively low sensitivity, identifying substantially fewer individuals with FASD despite overlap in the neurobehavioral domains assessed (Sanders, Hudson Breen & Netelenbos, 2017). Additional studies examining the construct and factorial validity of ND-PAE have also identified limitations in the proposed diagnostic structure. In particular, the adaptive functioning domain—which requires multiple symptoms including communication or social communication deficits—has been identified as particularly restrictive and may prevent otherwise affected individuals from meeting diagnostic criteria (Sanders, Netelenbos & Dei, 2020). Research examining the internal structure of ND-PAE further suggests weak construct validity and inconsistent clustering of symptoms across domains, raising concerns about whether the current criteria adequately capture the neurodevelopmental presentation associated with PAE (Sanders, Netelenbos & Dei, 2020).

Taken together, these findings suggest that although ND-PAE represents an important attempt to integrate prenatal alcohol exposure–related neurodevelopmental impairments into a

widely used psychiatric manual, it remains in need of further empirical validation and potential revision. ND-PAE fails to identify the majority of individuals with FASD because the criteria are too restrictive and fails to identify the neurodevelopmental impairments among individuals at the most severe end of the fetal alcohol spectrum. Further, individuals with fetal alcohol syndrome (at the extreme end of the fetal alcohol spectrum) will be misdiagnosed as having ND-PAE if diagnosed by a clinical team that does not include a doctor. Accordingly, many multidisciplinary FASD diagnostic systems continue to rely on established clinical guidelines and neurodevelopmental assessment frameworks rather than the ND-PAE criteria alone when identifying individuals affected by prenatal alcohol exposure.

FASD Umbrella: FAS, SE/AE, and ND/AE

Fetal alcohol spectrum disorder is – as its name states – a spectrum, so it is useful to conceptualize diagnostic outcomes using the umbrella term FASD (Helgesson et al., 2018). Patients who are diagnosed at the UW FAS DPN clinic with an FASD will have either Fetal Alcohol Syndrome (FAS), Static Encephalopathy / Alcohol Exposed, or Neurobehavioral Disorder / Alcohol Exposed under the FASD umbrella. Fetal Alcohol Syndrome (FAS) is a birth defect syndrome caused by exposure to alcohol consumption during pregnancy (Hemingway, 2024; Seaver, Odle & Davidson, 2011). FAS is characterized by growth deficiency, a unique cluster of minor facial anomalies, severe brain abnormalities, and PAE (Hemingway, 2024). Growth deficiency is determined by the individual's height or weight at or below the 10th percentile (Hemingway, 2024). The unique cluster of minor facial abnormalities is comprised of small eyes, a smooth philtrum, and a thin upper lip, with exact measurements defining 'small,' 'smooth,' and 'thin' described in a later discussion of the 4-Digit Diagnostic Code (Hemingway,

2024). The prevalence rate of FAS is estimated to be 1 to 3 per 1,000 live births (Hemingway, 2024).

The next classification within the spectrum is Static Encephalopathy/Alcohol Exposed (SE/AE). The term "encephalopathy" refers to “any significant abnormal condition of the structure or function of brain tissues” (Anderson, 2002). The term "static" means that the abnormality in the brain is unchanging; neither progressing nor regressing. The term "Static Encephalopathy" is used in this diagnostic system when the patient presents with significant structural, neurological, and/or functional abnormalities that strongly support the presence of underlying brain damage (Hemingway, 2024). Patients who receive the SE/AE diagnosis are those with severe brain abnormalities and prenatal alcohol exposure, but do not present with the growth and/or facial anomalies that meet criteria for FAS. Neurodevelopmental Disorder/Alcohol Exposed (ND/AE) is the diagnosis for patients who present with moderate brain dysfunction and prenatal alcohol exposure. The moderate brain dysfunction is defined by one or two domains of functioning that are two standard deviations below the mean/average in the patient’s age range (Hemingway, 2024).

Common Comorbidities with FASD

In the United States, it is estimated that about 90% of individuals who have FASD have co-occurring neurodevelopmental or mental health diagnoses (Astley 2010; Flannigan et al., 2022; Pei et al., 2011; Temple et al., 2019; Weyrauch et al., 2017). In childhood and adolescence, challenges with behavior often overshadow the neurological impairments of FASD, which can lead to a diagnosis other than FASD, in an effort to explain behavior challenges (Waite & Burd, 2023). In an Australian sample of patients with FASD, Connor et al. (2020) found ADHD (41.7%), sleep disturbance (61%), and executive functioning (78.4%) were the

three most common comorbidities reported. Several studies highlight the high likelihood that an individual with FASD will also have a diagnosis of ADHD, given that individuals with FASD are 10 times more likely to be diagnosed with ADHD than the general population (Weyrauch et al., 2017).

Fryer et al. (2007) found in their study evaluating conditions and outcomes for children with PAE that 95% of their alcohol-exposed group had ADHD as compared to 30% of their control group. O'Malley and Nanson (2002) concluded in their comprehensive review of research into FASDs and ADHD that children with FASD and ADHD comorbidities were unique in their ADHD presentation, specifically due to their earlier onset and unpredictable and inconsistent response to medication typically prescribed for patients with ADHD. Other frequently occurring comorbidities include disorders of the nervous system, conduct disorder, receptive/expressive language disorders, hearing impairment, and intellectual disabilities (Popova et al., 2016).

Secondary Conditions

Extensive literature addressing the known impacts of prenatally exposure to alcohol on cognition, communication, learning, memory, and behavior also acknowledges the secondary conditions that can occur in a number of domains for individuals with PAE (Hellemans et al., 2010). Research outcomes demonstrate that 94% of individuals with FASD report having experienced at least one mental health problem during their lifetime (Astley 2010; Petrenko et al., 2014). Among these secondary conditions include substance use disorder, depression, anxiety, and posttraumatic stress disorder (CDC, 2024; Clark et al., 2008; Hellemans et al., 2010; Pei et al., 2011). Depression and anxiety disorders are the widely endorsed secondary conditions in children and adults with FASD (Hellemans et al., 2010). Weyrauch et al. (2017) report that individuals with an FASD diagnosis are 11 times more likely to experience an anxiety disorder

than the general population. Furthermore, research examining the impact of adverse childhood experience (ACE) scores indicates that higher ACEs corresponded to increased risks for substance use disorder, attachment disorder, and post-traumatic stress disorder (Tan et al., 2022).

Symptom Overlap with other Neurodevelopmental Disorders

Given the number of symptoms that overlap with other neurodevelopmental disorders, no biomarker, and the fact that there is no singular presentation of FASD makes differentiating FASD from a diagnosis of autism spectrum disorder, global developmental delay, a communication disorder, ADHD, or oppositional defiant disorder (ODD), for example, particularly difficult (Glass & Mattson, 2017; Lees et al., 2022; Nash et al., 2008; Waite & Burd, 2023). Literature in the field of FASD demonstrates marked overlap of symptoms between FASD and ADHD, including inattention, executive functioning, working memory, attention, behavior regulation, impulse control, and processing speed (Waite & Burd, 2023). A child not on the fetal alcohol spectrum who has ADHD and needs support in addressing difficulty with impulse control may end up having a similar or the same accommodation as their peer with FASD who struggles with impulse control; however, the impact of executive functions may be far greater for a child with FASD and ADHD than a child with only ADHD (Khoury & Milligan, 2019; Kingdon, Cardoso & McGrath, 2016). Thus, targeted intervention programming and accommodations may still differ between the two, despite similar needs for support around executive functions.

Research has also demonstrated similar challenges and needs for support in regard to communication between autism and FASD (Bishop et al., 2007; Carpita et al., 2022), though Waite and Burd (2023) distinguish specific communication and social interaction differences that allow for more tailored accommodation recommendations between the two diagnoses. For

example, children with autism are more likely to struggle with initiating social interaction and using non-verbal communication, whereas a child with FASD is more likely to seek out social interaction, engage in interactive play, and express overly friendly behaviors (Bishop et al., 2007; Waite & Burd, 2023). So, although a child with autism and a child with FASD may equally benefit from interventions related to social interactions, the child with autism might be better served with an intervention around reciprocal play and initiating conversations and a child with FASD may need an intervention to learn skills around exercising personal boundaries.

In their study comparing 25 young school-age children with FASD to 26 typically-developing peers on measures of sensory processing, sensory-motor performance, adaptive behavior, school functioning, and behavior, Jirikowic, Carmichael-Olson & Martin (2008) found that children with FASD performed significantly worse across nearly all areas; that is, they had poorer sensory processing, more sensory-motor difficulties, weaker adaptive skills, lower academic achievement, and more behavioral concerns at home and school. The researchers also found that sensory difficulties were associated with poorer adaptive functioning and some academic weaknesses, suggesting that sensory problems may contribute to broader day-to-day challenges for children with FASD. A further discovery in this research indicates that children with FASD are about three times more likely than typically developing peers to show clinically significant sensory processing problems, including sensory over-responsivity to touch, sound, and visual input, as well as sensory under-responsivity, sensation-seeking behaviors, and poor auditory filtering. Specific sensory-motor weaknesses in children with FASD, including poor balance, coordination, fine-motor skills, visual-motor speed, and design-copying abilities led to further identified “neurological soft signs,” meaning subtle motor and perceptual challenges that

may affect handwriting, cutting, tying shoes, participation in sports, and other classroom or daily living activities.

Barriers for Obtaining and Disclosing an FASD Diagnosis

Research demonstrates that families experience significant challenges in regard to obtaining a diagnosis of FASD for their child (Coons et al., 2016; Coons et al., 2018; Mukherjee et al., 2013; Salmon, 2008; Sanders & Buck 2010; Watson et al., 2013; Whitehurst, 2012). In order to receive a diagnosis of FASD, individuals must find a qualified team of providers to conduct a diagnostic evaluation. Unfortunately, waitlists for diagnostic specialists and neuropsychologists are commonly long, and can take six months or more for the child to be seen – meanwhile, secondary conditions, as previously discussed, may develop as the child awaits an evaluation (Petrenko et al., 2014). Even with a diagnosis, limited knowledge – or lack of knowledge altogether of FASDs – may lead educators to overlook child’s need for tailored intervention services (Petrenko et al., 2014). The barrier of obtaining a diagnosis may prevent a child from getting the interventions and accommodations they need to be successful across domains of functioning.

In their systematic review of literature for studies examining interventions for individuals with FASD across the lifespan, Reid et al. (2017) highlight the systemic barriers families encounter when attempting to access interventions, including limited research across the lifespan for individuals with FASD, selection bias in study populations, inadequate consideration of caregiver and environmental influences, and inconsistency in intervention approaches. The lack of randomized control trials, selection bias in many studies due to recruitment of participants from clinics or through self-referral, and the lack of consideration of broader ecological contexts

perpetuate a continued challenge in addressing the barriers that impact the development and implementation of effective, accessible interventions for individuals with FASD.

Lack of Professional Training and Knowledge

Understanding the complexities of FASD, including its neurodevelopmental impacts and behavioral manifestations, is essential for developing interventions for the specific needs of this population (Adebiyi et al., 2019). The lack of knowledge about FASD permeates medical and mental health professions, the education system, the judicial system, and even social networks including friends and family (Petrenko et al., 2014). Across qualitative studies that have gathered interview information from caregivers of children with FASDs, a lack of trust in professionals due to their absence of understanding the multifaceted challenges for children with FASD is an immense barrier for families seeking and receiving adequate services (Coons et al., 2016; Sanders & Buck, 2010; Whitehurst, 2012).

A major challenge in obtaining a diagnosis is the limited number of providers who are capable of diagnosing FASD, as many physicians report a lack of training in assessing for potential PAE and knowing where to refer families for evaluations if they suspect or learn information that confirms PAE (Petrenko et al., 2014). Petrenko and colleagues (2014) found in their interview study that very few providers across medical, mental health, and education setting reported having had any formal education or coursework addressing FASD during their professional training. The fear of stigmatizing a caregiver or the child could be a barrier to asking important questions about exposures and therefore contribute to the negative judgments and beliefs society holds about FASDs.

The mismatch between an FASD diagnosis and appropriate IEPs may be due to a lack of understanding among educators, school psychologists, and related service providers about the

lifelong impacts of PAE and the complex profiles and outcomes of individuals who were prenatally exposed to alcohol (Kautz-Turnbull et al., 2024; Reedman, Breen & Wu, 2024). More research is vital to specifically determine approaches for supporting students with FASD using a strengths-based lens and including the voices of students with FASD and their families (Reedman, Breen & Wu, 2024). Training which is specific to FASD – as it relates to students in school settings – is needed across different professional groups, including teachers, school psychologists, and other educational professionals (Blackburn, Carpenter & Egerton, 2012; Lees et al., 2022).

School Psychologists. Psychological assessment is critical for developing and implementing appropriate accommodations and interventions for children with disabilities, including children with FASD (Pei et al., 2013). In educational settings, the need for both comprehensive and accessible interventions and resources is critical across students, caregivers, educators, and other key stakeholders, especially given the specific and variable developmental and behavioral challenges often experienced by individuals with FASDs (Farley et al., 2020). School psychologists are a federally mandated role in public schools tasked with the assessment, identification, and support of students with disabilities (U.S. Department of Education, 2015). This support includes – and is not limited to – utilizing standardized assessments and observations, supporting the development of IEPs and behavior interventions that are individually tailored to support a student’s needs, and working closely and collaboratively with teachers and families to implement evidence-based strategies to support learning and behavior (NASP, 2020).

Thus, school psychologists are uniquely positioned to identify, assess, and provide interventions for children with FASD (Lees et al., 2022). However, school psychologists must

have access to comprehensive training and up-to-date information about FASD in order to be effective in providing services and identifying individualized needs for the student alongside the special education team (Lees et al., 2022). Such training should address early detection and intervention, assessment strategies, and assessment battery considerations when contextualizing FASD and student needs. One of the key domains of the school psychologist practice model, as determined and defined by the National Association of School Psychologists (NASP), is collaboration (NASP, 2020). Collaboration with school-based teams is a requirement for comprehensive evaluations, and in addition to collaboration with teachers, service providers, and administration, collaboration with medical professionals and community organizations can be particularly effective and optimal for supporting a student with FASD and their family (Lees et al., 2022).

Teacher Training. Teacher training programs must be evaluated for their inclusive educational policies and training curricula to determine whether teacher certification benchmarks are truly meeting the needs of all special education student populations, especially those with neurodiverse profiles and needs (Reedman, Breen & Wu, 2024). Teachers may be unaware entirely that a student in their classroom has prenatal alcohol exposures or a diagnosis of FASD (Choate & Badry, 2019). It is vital that further research explore the extent of knowledge about FASD amongst teachers, how this level of knowledge does or does not impact teachers' approaches to educating students with FASD, and why (Reedman, Breen & Wu, 2024). It is clear from the literature that there is a need for greater knowledge for all teachers and that access to continuing education courses and resources is imperative for teachers to gain a deeper understanding of FASD. Kautz-Turnbull et al. (2024) exposed the limitations and barriers to access for teachers seeking training on FASD-informed interventions. With the majority of

offered trainings held in-person, the location, cost, and time of limited trainings offered are some of the major barriers for obtaining specialized training and professional development, and although there are resource websites in existence, none of them have been systematically developed and tested as an FASD-informed intervention for teachers specifically (Kautz-Turnbull et al., 2024).

School and Caregiver Challenges. Caregiver-reported experiences of the school system point to a frequently endorsed experiences of frustration, lack of trust towards teachers and school professionals, and resentment (Choate & Badry, 2019; Coons et al., 2018; Morrisette, 2001; Reedman, Breen & Wu, 2024; Salmon, 2008; Sanders & Buck, 2010). Because FASD is a spectrum disorder, unrealistic expectations and assumptions about a child's abilities and challenges by their teacher are reported by caregivers (Sanders & Buck, 2010). Caregivers feel judged by school staff who equate their child's behavior challenges with poor parenting and/or indifference toward their child's education (Coons et al., 2016; Coons et al., 2018; McCarthy et al., 2022; Morrisette, 2001; Opini, 2019; Whitehurst, 2012).

Furthermore, caregivers report that they themselves are often in the position of having to educate their child's teachers on what FASD is and how it affects their child's performance in school (Coons et al., 2016; Kautz, Parr & Petrenko, 2020; Petrenko et al., 2014). This can lead to a further disconnect between IEPs and the educational and behavioral needs of children with FASD, as caregivers' advocacy and knowledge about school-based interventions and services may be limited in comparison to a school psychologist or special education teacher. The scope of services and interventions necessary for supporting the success of the child in school may be under-identified and fail to meet a child's individual needs (Coons et al., 2018; Salmon, 2008; Whitehurst, 2012). Regardless of profession, be it special education teacher, school psychologist,

occupational therapist, or school administrator, Lees et al. (2022) emphasizes the importance of ongoing professional development opportunities that address supporting students with FASDs and their families, given that research and intervention strategies are continually emerging in this field.

Stigma and FASD

Consuming alcohol during pregnancy is a highly stigmatized behavior and considered a ‘moral failure’ in many Western societies (Binder et al., 2024). Stigma surrounding FASD is a multifaceted issue that impacts diagnosis, prevention, and support for children and their families. Within the vast literature of stigma research, four distinguishable types of stigma are noteworthy and relevant to the lived experiences of individuals with FASD and their families: public stigma, self-stigma, stigma by association, and structural stigma (Pryor and Reeder 2011 as cited in Roozen et al., 2022), with public stigma at the center (Figure 1). Understanding the interplay and impact of stigma in the context of FASD informs the challenges for caregivers in seeking support for their child.

Public Stigma

FASD-related public stigma may include beliefs about substance use that puts personal responsibility on the person who drank alcohol while pregnant and who ‘should have known better’ or ‘should have sought treatment for alcohol use before becoming pregnant.’ These moral judgments and beliefs minimize the broader context of situational factors that contribute to why a woman may have consumed alcohol during her pregnancy, including unawareness of being pregnant in the first place, limited access to healthcare, cultural beliefs, and lack of knowledge about the harmful teratogenic effects of alcohol, to name a few. The assumption that a child with an FASD diagnosis has a biological mother who is an alcoholic is inaccurate and

misrepresentative of a myriad of factors that may have contributed to prenatal exposure to alcohol.

Furthermore, blaming and holding the mother individually responsible ignores other variables that may have contributed to the child's FASD diagnosis, including research which explores the role of paternal alcohol consumption and drinking patterns (Bakhireva et al., 2011; Finegersh et al., 2015; May et al., 2025; McBride & Johnson, 2016). In their study, May et al. (2025) report that fathers of children with a diagnosis on the FASD spectrum reportedly drank higher quantities of alcohol and have more frequent problem drinking rates than fathers of control groups. Basel et al. (2024) discuss in their study how commonly FASDs are exclusively attributed to maternal alcohol use and exposure during their pregnancy and in social messaging around alcohol consumption targeting women, yet men tend to have riskier patterns of alcohol consumption (Lyall et al., 2021; Naimi et al., 2003). Using mouse models, Basel et al. (2024) found that paternal alcohol use induces FASD-related behavioral, growth, and patterning defects in the next generation. This begs the question, then, why biomedical studies do not routinely consider male drinking and the potential interactions between maternal and paternal alcohol use despite the established correlation between maternal drinking and paternal alcohol use, if not due in part to the established public stigma that is determined to attach the responsibility and blame to the pregnant woman (McBride & Johnson, 2016).

Self-Stigma

Self-stigma is the internalization of stigmatizing beliefs, including being aware of them and even agreeing with these stigmatized beliefs, their applicability to oneself, and a decrease in self-esteem (Corrigan et al., 2017). Self-stigma in the context of FASD involves feelings of shame, guilt, and a perceived lack of competence and can include biological mothers holding

themselves responsible for the outcomes of their alcohol use during pregnancy (Roozen et al., 2022). Even in situations where the biological mother was drinking before she was aware of her pregnancy, research has shown that biological mothers engage in self-blame for the effects of alcohol use on their child (Shankar, 2016). Self-stigma in women who consumed alcohol during pregnancy reduces and/or impedes the use of support services (Binder et al., 2024). Self-stigma can occur for individuals themselves who are diagnosed with FASD, as they may internalize negative beliefs about their diagnosis which can lead to lower self-esteem and lower self-confidence (Salmon & Buetow, 2012). In a survey study designed to explore reported quality of life from adults with an FASD diagnosis, Hargrove et al. (2024) exposed high levels of stress, low levels of quality of life, high levels of perception of stigma, and low levels of support. Research has further identified challenges with acceptance and the stigma attached to an FASD diagnosis given that adults with FASDs are less likely to be ‘accepted’ than individuals with other disabilities who similarly experience a range of behavioral, cognitive, emotional, and physiological challenges, such as autism spectrum disorder (Choate & Badry, 2019; Yorke et al., 2018).

Stigma by Association

Stigma by association extends the impact of stigma to caregivers and families related to the women who drank during pregnancy and the children diagnosed with FASD (Roozen et al., 2022). For example, adoptive parents of a child with FASD may take great lengths to explain and make clear that their child was adopted to avoid blame or stigmatization by their social groups and peers when disclosing the diagnosis of FASD (Whitehurst, 2012). Nonbiological caregivers and guardians of individuals with FASD can be held responsible for their child’s disability or behavioral difficulties (Bell et al., 2016; Roozen et al., 2022). A clear consequence of stigma by

association is social isolation and ostracization from community, which can further impact access to support.

Structural Stigma

Finally, the literature addressing structural stigma surrounding FASD discusses the punitive measures and public health initiatives that impact the experiences of children with FASD and their caregivers (Roozen et al., 2022). In the United States, a wide range of state-level policies exist and although some policies focus on early intervention, others are punitive and define PAE to a fetus as child abuse or neglect, which criminalizes biological mothers and perpetuates stereotypes and stigma around alcohol use during pregnancy (Roozen et al., 2022). With regard to public health initiatives, risk information about alcohol use during pregnancy can be informative and well-intentioned, though some campaigns present FASD as preventable which ignores the complexity of factors that are present for some women who consume alcohol during pregnancy, such as drinking before knowing they were pregnant, substance use disorder, and perceptions of what some consider to be ‘low-risk amounts’ of alcohol, which can unintentionally provoke stigma (Millum et al., 2019; Roozen et al., 2022; Zhu, Smith & Parrott, 2017).

Descriptive Model of Stigma

To further address and understand the direct outcomes of the interplay of stigma and FASD, Bell and colleagues (2016) developed a model describing stigma with three themes indicative of the key elements of stigma and the ‘loads’ placed upon those affected by an FASD diagnosis, including individuals with FASD, their biological mothers, and their caregiving families (Figure 2). These themes include personal responsibility and blame towards biological mothers, stigma felt and experienced by children and families, and the anticipated life

trajectories for children with FASD. The model highlights multiple stakeholders – ranging from biological parents, kinship and/or foster caregivers, adoptive parents, and individuals themselves with FASD – who are likely to be subjected to various forms of stigma associated with alcohol consumption during pregnancy and FASD outcomes. Further, this model highlights the importance of understanding how stigma impacts lifelong trajectories for each stakeholder represented.

Disclosure of an FASD diagnosis and subsequent access to necessary services are ultimately negatively impacted by the realities of various forms of stigma placed on individuals with FASD and their families (Dunbar Winsor, 2021). As Bell et al. (2016) discuss, stigma remains a considerable barrier in choosing whether to disclose alcohol use during pregnancy and decide whether to seek and disclose a formal diagnosis of FASD. Seeking help from support networks is often avoided because caregivers feel misunderstood and worried about the blame and shame that may accompany the disclosure of their child's diagnosis and needs (Sanders & Buck, 2018). Beyond social networks, the public stigma from healthcare professionals who lack knowledge about FASD can be isolating and undermining (Corrigan et al., 2017). Furthermore, fear of stigmatizing a child and their family could lead some clinicians to underdiagnose or avoid recording an FASD diagnosis altogether (Bell et al., 2016).

Undoubtedly, stigma associated with FASD is complex given the societal, interpersonal, and systemic layers that affect individuals with FASD, their families, and the professionals supporting them. Current prevalence estimates suggest that schools may have higher numbers of students with FASD than are reported, and that FASD remains widely underdiagnosed (Millar et al., 2017). Schools must be a place where all students have access to services, accommodations, and inclusive and supportive practices that are relevant to their needs and challenges. This is

critical for destigmatizing FASD and reducing families' reluctance to report alcohol use during pregnancy so that appropriate accommodations and interventions can be implemented in school to increase a child's access to learning and support.

Importance of Caregiver Involvement

Caregivers of children with FASD more often than not are required to be their child's advocate and thus are directly involved in treatments and interventions (Olson et al., 2009). Several landmark federal court cases were integral in shaping the way children with disabilities must be included in education, in addition to the emphasis on parental involvement when making decisions about learning environments, educational goals, and opportunities for learning. Caregiver advocacy and involvement in their child's education and intervention plans began with the *PARC v. Commonwealth of Pennsylvania* (1971) decision in which families advocated successfully for their child's right to equal access to education regardless of disability status. One year later, the ruling from *Mills v. Board of Education of District of Columbia* (1972) recognized that students who have disabilities ranging from physical, mental, and emotional, are entitled to and must be provided public education, thus guaranteeing the right to free public education for all children, regardless of disability. A significant impact of the passing of IDEA (2004) was the empowerment it provided caregivers to legally advocate for, and demand access to, educational rights of their child. Families became recognized as integral stakeholders in their child's education and became recognized as key, active stakeholders in their child's learning and educational goals (Kelty & Wakabayashi, 2020).

The reauthorization of IDEA in 1997 (U.S. Department of Education, 2015) further strengthened caregivers' inclusion and role in the special education process, including setting goals in their child's IEP, requesting meetings with a multidisciplinary team, and requesting

evaluations. Schools are responsible for guaranteeing the attendance of at least one caregiver at annual IEP meetings and triennial re-evaluation meetings, as required by federal law.

Additionally, IDEA (2004) requires schools to provide advanced notice of all meetings, offer and provide an interpreter as needed at the cost of the school, and deliver caregivers educational safeguards as determined by the state in which they reside. These legal requirements ensure and protect families' opportunities to consult and collaborate on their child's IEP formation, including creating or modifying IEP goals and accommodations. Strong family-school partnerships are made possible through recognizing caregivers as equal partners with educators.

Over several decades, family-centered care has remained the standard of practice for children with special needs across systems including early intervention, healthcare, and education (Olson et al., 2009). Several effective interventions for individuals with FASD include caregivers directly in the intervention that aim to improve parenting skills, train parents and caregivers to better advocate for services, build proficiency in connecting with community resources, and teaching caregivers specific skills to reinforce to promote generalization and maintenance of treatment outcomes (Paley & O'Connor, 2011). An important clarification on the use of 'caregiver' and 'parent' is necessary to address inconsistencies in the use of these two terms across interventions and programming to support families with children with FASDs. Though research demonstrates a high rate of nontraditional families for individuals with FASD, in which parents are rearing nonbiologically related children, such as adoptive, foster, and kinship (Foli et al., 2022), special education law uses the term 'parent' so many interventions that have been created to support this population use the term 'parent' in order to remain consistent with special education law. The term 'caregiver' allows for more inclusive and encompassing representations of situations where family structures are diverse, which is often the case for children with FASD,

and includes roles other than parent (Sanderson & Goldman, 2023). Still, the term ‘parent’ is most often and widely used in the language found in evidence-based interventions and supports that are established in the field.

As previously mentioned, stigma plays an insidious role in outcomes and interventions for children with FASD and their families. Experiences of stigmatization can have direct impacts on caregiver involvement in their child’s education, given research that has demonstrated a number of negative experiences between families and educators within the public school system, including lack of knowledge about FASD, perpetuation of harmful stereotypes and misunderstandings about FASD, failure of school personnel to listen to caregivers, inappropriately tailored support, lack of sufficient professional services at school, and perceived inability of the schools to effectively manage behavioral and learning difficulties (Chamberlain et al., 2017; Mitašíková & Vodičková, 2022; Swart et al., 2014).

Intersectionality of Race and Disability

Intersectionality, first articulated by Crenshaw (1989), describes how multiple aspects of identity—such as race, gender, disability—interact to create unique forms of disadvantage that cannot be better understood separately. Within education, intersectionality highlights that students are not simply ‘a child of color’ or ‘a child with a disability,’ but may experience overlapping oppressions that compound one another (Tefera & Fischman, 2024). This framework is particularly relevant to students of color with disabilities, including those with an FASD diagnosis, who often encounter systemic inequities. Federal and state agencies have long recognized the disproportionate representation of racially minoritized students in special education placement and exclusionary discipline practices (Cruz, Kulkarni, & Firestone, 2021); these disparities reflect not only racism or ableism independently, but the intersection of both.

Importantly, research suggests that children with FASD, particularly those from racially and ethnically minoritized backgrounds, are at increased risk of delayed or missed diagnosis, inequitable access to services, and disproportionate school discipline (Fryer et al., 2007; O'Connor & Paley, 2009; Poth et al., 2020).

Dis/ability Critical Race Theory (DisCrit) further conceptualizes how racism and ableism function as interdependent forms of oppression within schools in the United States (Annamma, Connor, & Ferri, 2012). DisCrit emphasizes how practices of labeling, separation, and “normalcy” reinforce marginalization and simultaneously shape the lived experiences of students of color with disabilities (Annamma & Morrison, 2018). For children with FASD, this means that challenges related to neurodevelopmental differences are often compounded by racialized barriers to identification, services, and disciplinary outcomes (Brown, Higgins & O'Connor, 2022; Poth et al., 2020).

The intersection of race and disability has a paradoxical nature, at times offering legal protections while simultaneously exposing children to heightened risks of stigmatization and exclusion (Tefera & Fischman, 2024). For caregivers, experiences of racism and ableism in broader social systems can create distrust toward schools and educational authorities. This distrust may hinder collaboration with teachers, administrators, and specialists (e.g., psychologists, occupational therapists, and speech-language pathologists), thereby limiting advocacy for needed supports. In turn, families may be hesitant to disclose an FASD diagnosis, fearing stigma or discriminatory treatment (Brown, Higgins & O'Connor, 2022; O'Connor & Paley, 2009). These dynamics underscore how intersectionality shapes not only student outcomes, but also the caregiver–school relationship central to educational planning and service delivery.

Special Education Law and Individualized Education Plan Requirements

As previously mentioned, IDEA (2004) mandates free and appropriate public education in the least restrictive environment for all children identified with a disability (U.S. Department of Education, 2015). Public schools cannot exclude children from public education solely on the basis of their disability and are required to provide the “identification, diagnosis, and classification” of special education services “free of bias and that use multiple sources of information” (Osgood, 2005, p. 105-106). Schools are also required to ensure that students with disabilities are guaranteed the right to “an instructional setting that [is] as close to that established for their regular education peers as feasible” (p. 106). Furthermore, specialized instruction must be delivered in the least restrictive environment for children with identified disabilities (Yell, 2019).

IEPs provide a legal framework for setting measurable goals and identifying accommodations for students who have an identified disability (Kurth et al., 2025; Xu & Kuti, 2024). A student’s IEP must include present levels of academic achievement and functional performance, measurable goals, specific instructional methods and supports, related services, accommodations and modifications to how and what a child is learning and what is expected of them, the extent to which the child will participate in the general education classroom environment versus a special education classroom or setting, and by high school, a transition plan (Mattson, Bernes & Doyle, 2019; U.S. Department of Education, 2018). IEPs are reviewed and updated annually by the special education team in order to evaluate progress that has been made for the specific goals outlined within the document and to make adjustments and revisions to goals, interventions, and accommodations (U.S. Department of Education, 2018). Because an IEP is required for every child who qualifies for special education services (as determined

through assessment and diagnoses), children with FASDs who qualify for special education must also receive an IEP that addresses their specific needs and all educational, social/emotional, and behavioral goals, as relevant. Children with FASDs must qualify for special education services under one of the 13 disability eligibility categories, given that FASD is not a disability that is recognized on its own as a qualifying disability.

Demographic Disparities in Access to Special Education

Although IDEA mandates that schools identify and evaluate students suspected of having disabilities (20 U.S.C. § 1412[a][3]), a growing body of literature suggests that demographic variables—including race/ethnicity, sex assigned at birth, caregiver stability, and educational setting—may influence referral, evaluation, and eligibility decisions (Andersen & Fallesen, 2015; Girvan et al., 2016; Quinn & Madhoo, 2014; Pears et al., 2015; Sullivan & Proctor, 2016; Welsh & Little, 2018). Literature documents the persistent overrepresentation of non-White students in specific disability categories (Sullivan & Proctor, 2016), as well as overrepresentation of non-White students in disciplinary incidents and exclusionary practices (Girvan et al., 2016; Welsh & Little, 2018). Sex differences in identification also warrant consideration, given that the literature reveals females are less likely to be referred for evaluation for disorders characterized by inattentive or internalizing symptom profiles (Quinn & Madhoo, 2014) and compared to males, females with neurodevelopmental conditions are more likely to exhibit less overt externalizing behavior and may therefore be overlooked in school-based referral systems that prioritize disruptive classroom behavior (Rucklidge, 2010). Given that many individuals with FASD present with executive functioning difficulties, attention regulation challenges, and internalizing symptoms, females may be at elevated risk for delayed or missed identification.

Placement instability and school mobility have been associated with fragmented educational records, interrupted evaluation timelines, and inconsistent special education service provision for youth in foster care (Andersen & Fallesen, 2015; Pears et al., 2015). Children in foster care placements experience additional systemic vulnerabilities that may affect access to special education services; although federal protections exist to promote educational continuity, high rates of school changes among foster youth may delay or disrupt special education evaluation processes (Hansson et al., 2018; Marcellus & Badry, 2023). In terms of academic settings, students who are homeschooled or parentally placed in nonpublic educational settings may encounter structural barriers in accessing special education services. Although IDEA mandates that districts fulfill Child Find obligations for all students residing within district boundaries (20 U.S.C. § 1412[a][3]), students who are parentally placed do not receive the same individual entitlement to FAPE as students enrolled in public schools, and service access may depend more heavily on district implementation practices and parent awareness of procedural rights (Yell & Bateman, 2019; Zirkel, 2018). Research further indicates that variability in family knowledge of special education safeguards can influence access to evaluation and services (Haines et al., 2017).

Frameworks for Intervention Development for FASDs

Developing accurate and evidence-based methods for identifying and supporting individuals with FASDs requires an understanding of the full spectrum of the disability and the many risk and protective factors postnatally for these children (Murawski et al., 2015). Among these factors include a stable and nurturing home, attachment, parent-child interaction patterns, cognitive appraisal, stress, and resource needs (Olson et al., 2009, Petrenko, 2015). A neurodevelopmental framework as developed by Kodituwakku (2010) and a conceptual

framework combining developmental and family systems theories (Olson et al., 2009) are valuable to explore when considering the development of FASD-specific interventions.

Neurodevelopmental Framework

Proposed by Kodituwakku (2010), the neurodevelopmental framework delivers conceptual tools for integrating multiple sources of data to design interventions for children with FASDs, including neuropsychology, cognitive neuroscience, genetics, and neuropharmacology. This framework emphasizes the dynamic reciprocal interactions between experiences and the neural system of the brain to best understand the neurocognitive profile of children with FASD and to develop appropriate interventions. Given highly endorsed challenges with executive functioning and behavior for individuals with FASDs, the neurodevelopmental framework advocates for interventions that target attention and self-regulation because of the more generalized benefits that these areas can broadly address rather than domain-specific skills (Kodituwakku, 2010). This framework posits that neuropsychology of FASD can be used to develop and offer guidelines for optimal outcomes of interventions specifically designed for children with prenatal alcohol exposures (Kodituwakku, 2010). These guidelines include considering the child's overall cognitive behavioral profile, using strategies appropriate for the child's zone of proximal development, providing early training in attention and self-regulation, providing enriched environmental input, and when appropriate, combining evidence-based behavioral and pharmacological intervention (Kodituwakku, 2010). Vygotsky's (1978) insights into the development of self-regulation and academic skills have significant implications for the development of interventions for children with FASDs particularly when considering the selection of appropriate tasks and strategies for training (Kodituwakku & Kodituwakku, 2011). Of note, this framework proposes that children with FASD may gain optimal results from

interventions that combine a use of precisely designed behavioral interventions and pharmaceutical drugs (Kodituwakku, 2010), which is beyond the scope of school-based services.

Conceptual Framework

Olson et al. (2009) provide a framework that merges developmental theory with family systems theory for better understanding the importance of caregiver and family involvement in the treatment of children with FASDs. This model highlights the necessity of multi-level evaluations and interventions, considering both individual developmental trajectories with familial contexts and simultaneously considering the risks and protective factors for this population. This conceptual framework posits that effective interventions should address the broader family environment to support the child's comprehensive development, given that the field of FASD research has highlighted the impact of parent-child interaction patterns including stress, confidence, environmental risks, and need for information and resources (Olson et al., 2009). By synthesizing multiple sources of information, Olson et al. (2009) emphasize interventions which attempt to reduce risk and increase protective factors for children with FASDs must integrate family systems theory to highlight the importance of family-level factors, as the family system can affect and maintain long-term changes.

Lived Experience Model

Interventions are likely to be most successful when they include direct child intervention and parent support (Petrenko, 2015). In positioning the conceptual framework from Olson et al. (2009) and the neurodevelopmental framework from Kodituwakku (2010), Petrenko (2015) proposed the inclusion of the lived experiences of parents of child with FASDs and providers as valuable information when developing interventions for this population, called the Lived Experience Model (Figure 3). Caregivers and service providers have “first-hand experience with

the current systems of care and have insight into what is beneficial and what is needed” (Petrenko, 2015, p. 200). The model illustrates the specific intervention needs and approaches across the lifespan that are recommended by participants from their study to meet the overarching themes of need for people with FASD. Deliberate inclusion of the voices and experiences of caregivers and service providers within the FASD community can inform intervention design and evaluation.

Multi-Tiered Systems of Support Framework

Multi-Tiered Systems of Support (MTSS) are frameworks that provide comprehensive, individualized support to students through evidence-based interventions in a tiered system increasing in intensity of intervention aligned with severity of need for each student (Nitz et al., 2023). MTSS is a proactive, evidence-based framework that is adopted in schools to provide academic, behavioral, and social-emotional support to all students, not just students with a suspected or confirmed disability (Greenwood et al., 2019). MTSS utilizes universal screening and progress-monitoring in order to provide the evidence that practitioners need when making intervention decisions (Greenwood et al., 2019; Preston, Wood & Stecker, 2016; Sullivan et al., 2024). MTSS is not a substitute for special education but instead is a framework that embeds a support system using tiered intervention to differentiate between learning disabilities and a need for better instruction (Preston, Wood & Stecker, 2016; Sullivan et al., 2024). This instructional differentiation and support are not limited to academic learning exclusively; in their systematic review study, Nitz et al. (2023) found that MTSS was found to be effective in elementary schools internationally, especially in terms of tiered support for behavior change. This is particularly salient for students with complex neurobehavioral profiles (such as those with FASDs) who need early, tiered supports for behavior and self-regulation—not just academic support. These

findings highlight the need for all school psychological practice to align with the ethical obligations as defined by NASP to utilize assessment methods for identifying strengths and needs, developing effective interventions, services, and programs, and for measuring progress and outcomes within a multitiered system of supports (NASP, 2020).

Evidence-Based Interventions and Accommodations to Support FASDs

The terms ‘accommodations’ and ‘interventions’ are widely and interchangeably used in education research and implementation, yet there is often a lack of distinction between and clear definitions of each term specific to public education (Harrison et al., 2013; Harrison et al., 2020). To provide clarity, interventions are defined as focused on improving a competency area to reduce the impact of a child’s impairment and thereby eliminate the need for accommodations (Harrison et al., 2020). Accommodations are the changes to instruction that still hold a student to the same standard as their peers without disabilities but provide differentiated support to mediate the impact of the child’s disability in accessing the general education curriculum (Harrison et al., 2013).

The use of evidence-based interventions and accommodations are a demonstrated pathway to support for children with FASD, especially through interventions that focus on caregiver support, attention, self-regulation, and adaptive functioning (Petrenko & Alto, 2017). The American Psychological Association (APA) defines ‘evidence-based practice’ as practices or programs that have been thoroughly evaluated via scientific research grounded in empirical evidence and have demonstrated the ability to produce reliable and positive outcomes (APA, n.d.). When considering whether an intervention may have utility in supporting students with FASDs, selecting interventions that have been validated and evaluated with specific relevance to the FASD community (e.g., families and individuals with FASD) is critical given the unique

presentation and difficulty for children with FASD to neatly fit into existing interventions and treatments. A critical aspect that impacts the supportive nature of an intervention for children with FASD is recognizing that no single strategy will work for all students with FASD. This is why an individualized approach and tailoring the program to a child's specific needs is necessary for appropriately supporting students with FASD. Although a specific strategy can be used across multiple developmental disorders, such as an executive functioning intervention that also supports a child with an ADHD diagnosis, for example, the full benefits of an intervention cannot be realized unless it is tailored to the unique strengths and weaknesses of the individual child (Kodituwakku, 2010).

In their review of patient records from the UW FAS DPN clinical database, Jirikowic et al. (2010) detailed the interdisciplinary team's recommendations for accommodations and interventions specific to a child's individual needs after their evaluation at the clinic. Accommodation recommendations included any adaptation or modification to the child's environment or routine to be implemented in their home, at school, in the community, or another setting. These recommendations often included accommodations for behavior and emotion regulation (supporting group participation, environmental structure changes), communication (using visual schedules or cues for interaction), executive functioning including organization and memory (access to checklists and memory aids), sensory-motor (such as headphones for cancelling noise, reducing sensory input, access to keyboarding), and team communication between home, school, and other providers (Jirikowic, Gelo & Astley, 2010).

FASD-Specific Interventions

A series of studies looking at intervention services for children with special needs demonstrate that children with FASD have a wide range of complex and specialized needs

(Flannigan et al., 2022; Jirikowic, Gelo & Astley, 2010; Mattson, Bernes & Doyle, 2019; Paley & O'Connor, 2011; Pei et al., 2017b). A child who is diagnosed at a young age is more likely to be placed in appropriate educational classes and with appropriate interventions to serve their specific needs (CDC, n.d.). However, early intervention for FASDs is challenging given that the effects of PAE are more clearly identified as deficits in higher-level cognitive functions, which do not appear until second and fourth grades, well past the window for early intervention services (Olson et al., 2007). Having access to intervention, especially early intervention, is a protective factor for children with disabilities and can positively impact and improve long-term development for individuals with an FASD diagnosis (Bertrand, 2009; Montague & Carmichael Olson, 2011; Pei et al., 2017).

After analyzing 622 patient follow-up satisfaction survey responses from the University of Washington (UW) FAS DPN clinical database, Astley (2014) discovered that more than 96% of patients felt interventions that were recommended by the interdisciplinary team met their needs, with 89% of patients reporting success in accessing those interventions. Furthermore, patients with a diagnosis of Static-Encephalopathy/Alcohol-Exposed (SE/AE) or Neurodevelopmental-Disorder/Alcohol-Exposed (ND/AE) under the FASD umbrella were as likely to report successfully accessing and having their needs met by the recommended interventions as patients with a diagnosis of Fetal Alcohol Syndrome (FAS). This finding suggests that the diagnostic labels of SE/AE and ND/AE were as effective as FAS in providing access to intervention services and therefore early diagnosis for children with FASD is critical for effective and early intervention to support the challenges associated with prenatal alcohol exposure. The families of patients who were 0-5 years old reported the greatest access to interventions and having their needs met by the recommendations from the interdisciplinary

team, whereas patients over the age of 18 reported less success finding and accessing the recommended interventions and services, further highlighting the need for early identification and diagnosis so that families can access intervention services as early as possible. Early identification and diagnosis appear to improve outcomes for access to resources and interventions.

A study conducted by Popova et al. (2016) aimed to estimate the number of children aged 5 to 14 years with FASD receiving special education services in Canada and to assess the associated costs of services. Their study estimated that approximately 6,520 children with FASD were receiving special education services in Canada during the 2011–2012 academic year, with a higher prevalence of FASD among male students in special education and the total cost of providing special education to children with FASD estimated at about 53.5 million Canadian dollars for the 2011–2012 academic year. Although the purpose of the study was to highlight the significant demand for special education services among children with FASD in Canada, it also draws awareness to the challenges children with FASD face in accessing appropriate interventions and accommodations, including underdiagnosis, substantial variation in resource allocation, and regional differences in special education services (including availability and quality), which can result in unequal access to whatever interventions for children with FASD do exist. This result is echoed by the exploration of educational interventions designed to support school-aged children affected by FASD from Taddeo, Cole & Millians (2011). Their research emphasized that, although effective interventions for children with FASD do exist, access to these programs is often limited by resource constraints including training, funding, and policy support at both the educational and governmental levels.

Family-Centered Interventions. Because caregiving in a stable, nurturing home environment is protective against secondary conditions for children with FASDs, caregiver training and interventions help caregivers to better understand and respond to the neurodevelopmental differences of their child. Interventions that highlight family systems and caregiver education and training focus on the caregiver-child relationship, psychoeducation, positive behavior support, mentoring, and accessing community resources (Bertrand, 2009; Betts et al., 2022; Families Moving Forward, 2026; Grant et al., 2004; Kable, Coles & Taddeo, 2007; Keightley et al., 2018; Koren, 2014; Leenaars et al., 2012; O'Connor et al., 2006). Among these include Break the Cycle, Coaching Families, Families Moving Forward, Parent-Child Assistance Program, and Parent-Child Interaction Therapy.

Break the Cycle (BTC) focuses on the parent-child relationship with biological mothers who struggle with substance use and their young children (Koren, 2014; Petrenko & Alto, 2017). This intervention combines a comprehensive and coordinated range of services and is delivered via in-home visitation and community outreach on an as-needed basis. Outcomes of this intervention have shown a decrease in maternal substance use, improvements in self-reported maternal mental health, and increased relationship capacity between mother and child (Koren, 2014).

Coaching Families (CF) is an intervention that aims to educate families about FASD, help them access resources in their community, and engage families in successful advocacy for their child (Leenaars et al., 2012; Petrenko & Alto, 2017). Coaching Families is delivered through goal-based mentorship in the patient's home on an as-needed basis. This intervention has been particularly effective in helping caregivers experience an overall decrease in needs for

accessing resources, an increase in goal attainment, and a significant decrease in overall caregiver stress (Leenaars et al., 2012).

Families Moving Forward (FMF) has been demonstrated as an effective therapeutic intervention which modifies specific parenting attitudes and responses toward child problem behavior to reduce rates of the problem behavior and improve overall family functioning (Bertrand, 2009; Families Moving Forward, 2026; Petrenko & Alto, 2017). This intervention is delivered for nine to 11 months, every two weeks, for 90-minute sessions. This has been adapted to allow for several modalities, including in-home sessions and telehealth sessions to accommodate distance and virtual appointments during and after the COVID-19 pandemic (Petrenko et al., 2021). Outcomes of this intervention include improvements in parenting self-efficacy and self-care, a clear report of family needs being met, and an overall reduction in problem behaviors for their child (Petrenko & Alto, 2017).

The Parent-Child Assistance Program (P-CAP) for Mothers with FASD provides support to women who struggle with alcohol and substance in connecting to and coordinating community resources and services and ensures a safe environment for both the mother and child (Grant et al., 2004; Petrenko & Alto, 2017). This is a 3-year intervention served in the child's home. Outcomes of this intervention include a reduction in the mother's drug and alcohol use, increased use of medical and mental health care services, and eventual acquisition of housing that is stable and safe for both the mother and child (Petrenko & Alto, 2017).

Parent-Child Interaction Therapy (PCIT) is an effective evidence-based intervention for parents and child that focuses on improving the parent-child relationship (Lieneman et al., 2017). For the purposes of making PCIT more relevant to children with FASD, 'parent' extends to caregivers and family members who participate in child rearing, given that many children with

FASD are in foster care or adoptive care situations. The aims of PCIT in the context of FASD intervention services include increasing appropriate social skills, reducing problem behavior, and creating a positive discipline program in collaboration with the family (Bertrand, 2009; Petrenko & Alto, 2017). A 14-weeks, 90-minute intervention is delivered weekly either in clinic or in-home with modifications and has been shown to improve child behavior problems and decrease parent stress for this population.

Self-Regulation and Attention Interventions. Children with FASD often struggle with deficits in attention and self-regulation (Kable et al., 2016). The Alert Program, Parents and Children Together (PACT), and the Computerized Progressive Attention Training (CPAT) are some of the interventions that address this challenge and target self-regulation skills (Bertrand 2009; Kerns et al., 2010; Nash et al. 2015; Petrenko & Alto, 2017; Wells et al., 2012). The Alert Program for Self-Regulation aims to improve self-regulation skills through sensory integration and cognitive processing activities that are delivered in-clinic in 3 stages over a 12-week intervention course (Nash et al., 2015). Improvements in inhibition, affect recognition, and parent-reported behavior regulation are primary outcomes of this intervention, though social skills and behavioral programs did not have a significant change after implementation of this intervention (Nash et al., 2015; Petrenko & Alto, 2017).

PACT is an intervention that adapts and incorporates components from the Alert Program for Self-Regulation as well as treatment strategies from treatment strategies from traumatic brain injury (TBI) literature (Bertrand, 2009; Petrenko & Alto, 2017; Wells et al., 2012). Delivered in-clinic over 12 weeks, parent-reported improvements in executive functioning and emotional problem-solving were noted as outcomes that benefitted the children enrolled in the intervention (Wells et al., 2012). Finally, the CPAT intervention uses computerized training on four tasks

(sustained attention, selective attention, orienting of attention, and executive attention) in combination with coaching in metacognitive strategies and support. This intervention can be used in schools and is delivered alongside one-on-one coaching four times per week for 30-minute sessions for a total of 16 hours of intervention. Outcomes of this intervention include improvements in sustained and selective attention, spatial working memory, and reading and math fluency (Kerns et al., 2010; Petrenko & Alto, 2017).

Social Skills and Behavior Interventions. Research has demonstrated the prevalence of children with FASDs who exhibit considerable social skills deficits which often continue into adulthood (Bertrand, 2009; Carmichael-Olson et al., 1998). Some interventions have been created to address deficits in social skills and social integration for children with FASD, including Good Buddies, Kid's Club, and a theatre-based intervention at the high school level (Keightley et al., 2018; O'Connor et al., 2006; Sparks-Keeney et al., 2011).

Good Buddies is a children's friendship training intervention that aims to teach individuals with FASD appropriate social skills (O'Connor et al., 2006). Such skills could include how to join a group, share with others, or manage feelings when being teased by another child (O'Connor et al., 2006). The Good Buddies intervention uses a group format to teach these skills over 12 weekly sessions with both parent and child groups (Bertrand, 2009; O'Connor et al., 2006; Petrenko & Alto, 2017). Sessions are organized around building the skills for the child to host a play date, emphasizing friendship skills, and are tailored to the neurodevelopmental needs of children with FASD. Outcomes from this intervention have included an improvement in the child's use and knowledge of social skills, improved behavior problems per parent report, improvements in the child's self-concept/self-esteem, and evidence that the intervention was

equally effective for both groups of children – those with FASD and children who do not have FASD.

Kid's Club was developed as a community-based social skills program for children 7-12 years old that accommodates the sensory needs of children with FASD (Sparks-Keeney et al., 2011; Petrenko & Alto, 2017). Parent and child sessions take place weekly for 90-minute sessions over the course of seven weeks, led by occupational therapy master's level students. Outcomes of this intervention indicate improvements in the child's peer social skills per parent report (Sparks-Keeney et al., 2011).

Finally, Keightley et al. (2018) investigated the use of a theatre-based intervention for Indigenous youth with FASD, motivated by a lack of previous research that has explored the role of theatre-based interventions with adolescents who struggle with emotional, behavior, and cognitive challenges related to FASD. The theatre-based intervention was held five days a week for 4-hour session over a period of four weeks. The researchers found that an increase in self-confidence and greater communication of individual feelings and emotional needs were the positive outcomes of this pilot intervention.

Executive Function Interventions. Executive functions are a commonly endorsed challenge and underlie many of the poor outcomes for children with FASD (Betts et al., 2022). Betts et al. (2022) systematically reviewed executive function interventions specifically designed for children with a history of PAE and found that although some interventions show promise, such as The Alert Program for Self-Regulation, Metacognitive Strategy Training, and Family-Focused Interventions, the overall effectiveness of executive function interventions for children with FASD remains limited. Of the interventions that showed moderate effectiveness, the ones which focused on training specific executive functions, such as working memory, inhibitory

control, and cognitive flexibility, and ones which included families, were more likely to be beneficial for children with FASD than other neurodevelopmental disabilities (Betts et al., 2022). Additionally, the review highlighted the use of computerized cognitive training to support and target working memory and inhibitory control such as Pei and Kerns (2012) who reported moderate effectiveness with computer games that were designed to enhance cognitive skills in children with FASD.

An additional intervention that has shown positive outcomes in executive functioning skills is the GoFAR intervention developed by Coles et al. (2015). This intervention is aimed at increasing planning, organization, and goal setting. The intervention is delivered using a computer over ten, 1-hour sessions. The outcome of this study was a decrease in disruptive behaviors, per parent report. Betts et al. (2022) note that a significant limitation of the existing intervention studies in the literature is the variability in intervention delivery, intensity, and duration, which underscores the need for more standardized approaches to assess the effectiveness of studies and outcomes related to executive function interventions for children with FASD.

Math Intervention. Deficits in mathematical functioning have been reported for children with FASDs (Kable, Coles & Taddeo, 2007). The Math Interactive Learning Experience (MILE) intervention was specifically created to facilitate math learning in children who have a history of prenatal alcohol exposure. This program is delivered through a six-week course of one-on-one tutoring sessions. The session content is adapted specifically to meet the needs and appropriate academic level of the child. Additionally, parents receive training in behavioral regulation skills to increase their child's readiness to engage in the session and learn (Bertrand 2009; Kable, Coles & Taddeo, 2007). Significant knowledge gains in math at five-month follow up, as well as

caregiver-reported reductions in problem behaviors, are successful outcomes of this intervention (Kable, Coles & Taddeo, 2007).

Accommodations and Other Approaches

There is no singular metric that is agreed upon across disciplines to determine what makes an accommodation ‘effective’ (Lovett & Nelson, 2021). In fact, Lovett and Nelson (2021) concluded in their systematic review of academic accommodations that even the most ‘common’ accommodations have little to no experimental studies that directly investigate the efficacy across groups of students. However, a commonly held standard for evaluating effectiveness is whether it has positive effects and outcomes on the students who are targeted for the intervention (Lovett & Nelson, 2021).

Some existing accommodations and interventions that are not specifically created for children with FASD, but rather for any child with disabilities who experiences challenges in school, have demonstrated positive outcomes for children with FASD (Gunn, 2013). This may be because children with FASD may experience deficits that are similar to those of children with other disabilities, such as ADHD or ASD (Safer-Lichtenstein et al., 2024). One example is with executive functioning, which is a typical area of challenge for children with FASD and for children with ADHD and has been shown to be uniquely associated with poor academic outcomes (Safer-Lichtenstein et al., 2014, Tamm et al., 2014). Executive functions include inhibition, impulse control, planning and organizing, and emotional regulation (Millar et al., 2017). Common accommodations in classrooms for children with ADHD who struggle with executive functioning include extended time for assignments and tests, preferential seating, and access to a calculator to mathematics, for example (Lovett & Nelson, 2021). Because a child with FASD may similarly struggle with flexibility, planning, inhibition, and attention, they may

benefit from existing accommodations that are typically used to support a child with ADHD, including the ones stated above (Safer-Lichtenstein et al., 2024). An overlap of challenges between students with FASD and ADHD may indicate that using existing accommodations for executive functioning support may be useful for students with FASD (Safer-Lichtenstein et al., 2024).

Additional studies that evaluate the impact of FASD indicate significant challenges with sensory processing, motor control, adaptive and academic achievement (Jirikowic, Olson & Kartin, 2008; Millar et al., 2017). Common accommodations that support these challenges for students with or without a diagnosis of FASD include supports for group participation, visual schedules, memory aids and checklists, keyboarding, and headphones, to name a few (Jirikowic, Gelo & Astley, 2010). These existing accommodations may also be useful for a child with FASD in supporting sensory processing, adaptive, and academic needs.

In summary, existing interventions and accommodations that are available for all children with disabilities, regardless of the specific disability, may meet *some* of the needs of children with FASD; however, they may not fully capture and address the unique complexities and needs of children on this spectrum given the heterogeneous nature of the fetal alcohol spectrum (Bertrand, 2009). The search of the literature resulted in a persisting gap in acknowledging which accommodations and/or interventions that are designed for students with other disabilities may also support students with an FASD diagnosis. Despite studies that have been conducted to determine the needs of children with FASD and provide suggestions for accommodations and intervention programming, further research is needed to determine to what extent the existing services and supports are effective in supporting the complex needs of a child with FASD.

Flexible approaches to teaching children with FASD in conjunction with additional individualized support remains critical for supporting these students (Millar et al., 2017).

Comparing Team Evaluation Approaches Between Schools and Diagnostic Clinic

When a child is referred for a special education evaluation, a school-based special education team evaluates the child for services using a multidisciplinary approach, whereas in a diagnostic clinic, providers evaluate using an interdisciplinary approach. In multidisciplinary evaluations, professionals conduct separate discipline-specific assessments that together comprise a child's evaluation but may lead to fragmented interventions and accommodations (Castro-Kemp & Samuels, 2022). In contrast, interdisciplinary evaluations integrate diverse expertise through interactive, shared communication; this model has produced higher provider satisfaction and improved follow-up care (Gerdtz et al., 2018). To examine the features of and differences between each approach, a discussion of school-based and clinic-based evaluations is provided.

School-Based Multidisciplinary Evaluation

Children should qualify for special education services based on their needs as a direct result of their disability – regardless of what caused the disability – and individualized needs should drive interventions and accommodations, not the diagnosis (Pei et al., 2017a). Because FASD is not one of the disabilities that qualifies a child for special education in the United States public school system, it may be more difficult for a child to be deemed eligible for services based on an FASD diagnosis (Petrenko et al., 2014). The diverse and overlapping symptoms of FASD do not fit 'neatly' into one of the 13 eligibility categories as defined by IDEA (2004), such as Specific Learning Disability, ADHD, ASD, or Other Health Impaired. Furthermore, many children with FASDs may exhibit impairments that are just below the threshold cutoff to be

considered ‘significant enough’ of an impact to their learning and therefore to qualify for special education services. Children whose disabilities are more ‘straightforward’ and more widely understood (such as autism or ADHD) more easily qualify for special education services and tend to have fewer secondary conditions compared to children with FASDs (Petrenko et al., 2014).

In order to determine eligibility for special education in public schools, a school psychologist, along with other members of the school-based multidisciplinary team, must conduct a comprehensive evaluation of the child after a referral is made (*Forest Grove School Dist. v. T. A.*, 2009; Ofiesh, 2006; Yell et al., 2006). Psychological assessment is critical for developing and implementing accommodations and interventions for all children with disabilities, including children with FASD (Pei et al., 2013). A school psychologist’s job is not just selecting but also interpreting psychological assessments in educational settings for children with disabilities. In order to best serve students with disabilities, including students with FASD, school psychologists must engage in comprehensive evaluation procedures, suggest evidence-based interventions and accommodations specific to the disability, and encourage and foster collaboration and communication with all stakeholders to the best of their ability and within their capacity constraints.

A multidisciplinary team includes school psychologists, families, classroom teachers, and specialists which can include occupational therapists, physical therapists, and speech-language pathologists. A key aspect of a school psychologist’s role in the comprehensive evaluation of the child is to ensure that they are assessed in the domains of cognitive abilities, social-emotional skills, adaptive behaviors, and academic achievement to capture the full cognitive, adaptive, and learning profile of the child (Millians, 2015). Psychological assessments evaluate these domains

using specific, standardized tests and measures and integrate multiple data sources to identify and describe brain dysfunction, including standardized assessments, interviewing, observing the child in the classroom and school environment, and questionnaires (Harrison, Lee & Suhr, 2021). A school psychologist decides which assessment batteries to select when evaluating a child and the rationale for making those decisions should always consider a child's cultural background, English language proficiency, and relevance to the referral. For example, if a child's first language is not English and their exposure to the English language has been limited at the time of evaluation, it may be more appropriate to use a nonverbal assessment to report that child's cognitive ability rather than a 'language-loaded' assessment.

Equally important to assessing a child's strengths and challenges with standardized assessment tools is direct observation of the student and interviewing and gathering questionnaire data from caregivers, teachers, and the student themselves, when appropriate (Alperin et al., 2023; von der Embse et al., 2019). Observation of the student provides direct insights into how the student behaves and interacts with their peers and teachers in a natural setting (e.g., classrooms, playgrounds). This is a necessary component of the evaluation process, given the data that can be obtained during in-the-moment interactions and learning opportunities. Furthermore, observational data captures both contextual and situational aspects that may influence a child's behavior and academic performance, which is not always present or evident when testing a student alone in 'ideal' conditions (e.g., quiet office, 1:1 ratio, regularly offered breaks and accommodations). Ultimately, observations can reveal antecedents to a child's specific behaviors, patterns of inattention, or difficulties with social skills and adaptive functioning, which are common challenges for children with FASD.

Interviewing caregivers and teachers provides the school psychologist with important qualitative data about the child's developmental and educational history, current functioning across settings (e.g., home and school), and perceptions of the child's strengths and challenges. The insight gained from these stakeholders allows the school psychologist to triangulate information from the standardized and formal testing they conduct with the information gathered from the interview to gain a more accurate description and picture of the child's strengths and challenges. Interviewing can be especially important and helpful for establishing and building rapport with the child's caregivers, which fosters ongoing collaboration and caregiver involvement. To supplement interview data, questionnaires – standardized rating scales – allow the school psychologist to quantify or put quantitative power to the qualitative statements from caregivers and teachers. For example, a teacher might say in an interview that a child exhibits an externalizing behavior 'all the time' yet questionnaire results indicate that the behavior occurs no more often than their peers, for example. Rating scales are frequently used by school psychologists and the direct connection with these scales to problem identification and development of intervention and planning is particularly important for students with FASD (Gross, Farmer & Ochs, 2019). This quantitative data collection through questionnaires about a child's behaviors, emotions, and academic functioning enables the school psychologist to compare scores to normative samples to best identify areas of strengths and challenges for the child. For a comprehensive evaluation, there must be multiple informants (e.g., caregivers and teachers) across settings when using these questionnaires.

The assessment and perspective from multiple disciplines are particularly helpful in the case of FASD since the symptoms and impact of the disorder do overlap and cross over to so many areas of social and health services (Flannigan et al., 2024). Additionally, the assessment

process itself ideally involves a multidisciplinary team that relies on the input from each member before a diagnosis is made (Chudley et al., 2005). Because of the number of disciplines involved in comprehensive assessment for a child with FASD as well as support services involved, different perspectives are vital in ensuring that all educators and service providers have their scope of practice and expertise considered and incorporated in the evaluation (Chudley et al., 2005).

UW FAS DPN Clinic-Based Interdisciplinary Evaluation

The FAS DPN is a network of community-based clinics in Washington State linked by the core clinical research training clinic at the Center on Human Development and Disability at the University of Washington in Seattle, Washington. The network was established in 1993 through support from the March of Dimes, Centers for Disease Control and the Chavez Memorial Fund (Hemingway, 2024). In 1995, further support was received from the Washington State Department of Social and Health Services through the enactment of Senate Bill 5688. Each clinic in the network uses the same interdisciplinary approach to diagnosis and the same systematic method of diagnosis, the 4-Digit Diagnostic Code. Over the past several decades, the network clinics have been located in Yakima, Spokane, Pullman, Everett, Tacoma, Bothell, and Federal Way, as funding permitted. As of 2024, the core clinic at the University of Washington in Seattle and the network clinic in Bothell are the only FAS DPN clinics currently open. Over 3,300 patients have been diagnosed to date. The mission of the FAS DPN is primary and secondary prevention of FAS through screening, diagnosis, prevention, training, and research (Hemingway, 2024).

Evaluation Procedure at UW FAS DPN Clinic. Patients are eligible to attend the FAS DPN if they are under 22 years of age and have a confirmed PAE at any level. An evaluation day

at the UW FAS DPN clinic consists of two evaluations for two patients, with ages ranging from infancy up through 21 years of age, with one patient in the morning (8:30am-12:30pm) and the second patient in the afternoon (12:30pm-4:30pm). The structure of the evaluation (Figure 4 and Figure 5) begins with the patient receiving a height, weight, and head circumference measurement, as well as taking a clinical photograph of their face. Caregivers/patients are requested to provide consent for the FAS DPN to collect all records on the patient (birth, medical, school, intervention, mental health, placement, etc.) before the patient's appointment. These records are reviewed by the Program Assist and presented to the interdisciplinary team in the first 30 minutes of the evaluation, followed by test selection by the SLP, OT, and psychologist. While the SLP, OT and psychologist conduct a 2-hour interdisciplinary evaluation, the team pediatrician conducts a one-hour clinical interview with the patient's caregiver(s). Following testing, the pediatrician conducts a targeted physical exam.

The clinical team reconvenes for one hour to derive the 4-Digit Code and compose a comprehensive intervention plan that covers numerous topics from caregiver respite to patient medication management, educational recommendations and accommodations, etc. The caregiver(s) then joins the team for a 30-minute feedback meeting in which the results of the assessment are provided and discussed with the family. The patient leaves with a diagnosis and intervention plan. A comprehensive medical summary is sent to them in a few weeks. The team psychologist schedules a 30-minute follow-up meeting to discuss the recommendations once the family has had time to look over the recommendations and form any questions they may have about the evaluation and/or report.

Washington State FAS DPN Diagnostic & Screening Tools and Training

The 4-Digit Diagnostic Code

The UW FAS DPN clinic uses the 4-digit Diagnostic Code to evaluate and diagnose every patient that is seen at the clinic. The 4-Digit Diagnostic Code was first designed and published in 1997 (Astley & Clarren, 1997) and has since been revised and updated, with its current fourth edition (as of 2024) used by FASD diagnostic teams worldwide. The four digits of the code reflect the magnitude of expression of the four key diagnostic features of FASD in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain abnormalities, and (4) PAE (Hemingway, 2024).

The 4-Digit Diagnostic Code is generated at the completion of each patient's diagnostic evaluation using information recorded on the FASD Diagnostic Form (Hemingway, 2024). There are 256 possible 4-Digit Diagnostic Codes ranging from 1111 to 4444, with only 108 of the 256 codes falling broadly under the umbrella of FASD in accordance with the FASD 4-Digit Code, which are collapsed into six FASD diagnostic categories and further collapsed into three clinically meaningful diagnostic categories under the umbrella of FASD: Fetal Alcohol Syndrome (FAS), Static Encephalopathy/Alcohol-Exposed (SE/AE), and Neurodevelopmental Disorder/Alcohol-Exposed (ND/AE). Individuals with PAE often present with other prenatal and postnatal risks that may adversely impact growth and development in addition to alcohol exposure. These additional risks are documented in the clinic's diagnostic forms and evaluation report. A free copy of the Diagnostic Guide for Fetal Alcohol Spectrum Disorders, 4th Edition is available at the Washington State FAS DPN website.

The 4-Digit Code is a fully integrated and highly successful screening, diagnostic, prevention and surveillance program in Washington State (Astley et al., 2002; Astley, 2004; Hemingway, 2024). A major benefit of using the 4-Digit Diagnostic Code is that it increases diagnostic precision and accuracy using objective, quantitative measurement scales, image analysis

software, and specific case definitions (Hemingway, 2024). Furthermore, it allows for diagnosing the full spectrum of outcomes observed in individuals across all ages and all levels of PAE, using an intuitively logical 4-digit numeric approach to report outcomes and exposure that clearly and objectively reflect the magnitude of growth deficiency, FAS facial phenotype, brain abnormality and PAE (Hemingway, 2024). Additionally, the 4-Digit Diagnostic Code documents the presence of PAE and all other prenatal and postnatal adverse exposures and events that can also adversely impact outcomes for the patient (Hemingway, 2024). The 4-Digit Diagnostic Code also provides a universal language of numbers that can be grouped and regrouped into any number of diagnostic categories under the umbrella of FASD and assign diagnostic names that best meet the widely varying medical systems of care worldwide – which is critical as the clinical and research fields of FASD strive to achieve consensus on diagnostic criteria worldwide (Hemingway, 2024). An example of the 4-Digit Code Diagnostic Form used in the UW FAS DPN clinic can be found in Appendix A. To provide an example of the 4-Digit Code, imagine that a patient presented at the clinic with moderate growth deficiency, all 3 FAS facial features, severe brain dysfunction, and high prenatal alcohol exposure. This patient would receive a 4-Digit Code of 3434 and a diagnosis of FAS:

FASD 4-Digit Code						
	3	4	3	4	3	3
Rank						
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2-5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none
	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks

FASD Umbrella					
3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain	Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	fac	severe	exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe	exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed			moderate	exposed

(4-Digit Code Diagnostic Guide for FASD, Astley Hemingway, 2024)

FASD diagnostic guidelines are not universal and therefore can vary in other clinics, including the use of the Canadian (Cook et al., 2016), Australian (Bower et al., 2017), and Hoyme diagnostic guidelines (Hoyme et al., 2016). Hemingway et al. (2019) conducted a comparison of the 4-Digit Diagnostic Code, Canadian 2015, Australian 2016 and Hoyme 2016 diagnostic guidelines. This research uncovered significant variation across the four systems, with 82% of patients diagnosed with FASD by at least one system and only 11% diagnosed by all four (Hemingway et al., 2019).

The 4-Digit Code enhances the accuracy and precision of an FASD. The 4-Digit Code includes FAS Facial Photographic Analysis Software (Astley Hemingway, 2026), the Lip-Philtrum Guides, and in-person and online trainings. All diagnostic tools and the FASD 4-Digit Diagnostic Code Online Course are distributed electronically and are available for free on the Washington State FAS DPN website.

FAS Facial Photographic Screening/Diagnostic Tool. In 1996, the computerized FAS Facial Photographic Screening/Diagnostic Tool was developed by Dr. Susan (Astley) Hemingway at the UW FAS DPN. A Windows-based version of the software was created in 2003 for distribution to medical/research professionals and has been updated several times to its current 3.0 version, as of 2026 ((Astley) Hemingway, 2026). The tool measures the magnitude of expression of the three facial features of FAS as defined by the FASD 4-Digit Code (small palpebral fissures, smooth philtrum, and thin upper lip) from a digital facial photograph (Hemingway, 2024). The Washington State FAS DPN, as well as the Canadian and Australian systems, encourage and advise using the FAS Facial Photographic Analysis Software to measure the key facial features of FAS using 2D digital photos of the patient (Astley, 2015). Analysis of over 3,000 patients has confirmed that photo measurements rather than direct facial

measurements with a ruler are a more accurate measurement of the three key facial features of FAS (Astley, 2015; Astley, 2018). The Washington State FAS DPN website provides guidance for taking the three photographs to be analyzed using the software.

A facial photographic analysis can be conducted in approximately ten minutes. The software is designed to measure the magnitude of expression of the three key facial features of FAS. To use the software, the user opens three 2D digital facial photographs (frontal view, 3/4 view, and lateral view) into the software program, enters the patient's name, birth date, photo date, gender, race, measures the 3 facial features using special image analysis tools, documents the presence of any other facial anomalies, and documents the quality of the photos (Hemingway, 2024). From this information, the software automatically computes the FASD 4-Digit Code Facial ABC-Score and the 4-Digit Facial Rank. The software stores all photo analysis information in a database that can be exported to Microsoft Excel, and the user can print a one-page "FAS Facial Photographic Analysis Report" to be included in the patient's clinical file (Appendix B). The report includes a summary of the facial analysis and the three photos. Additional guidelines are provided on the Washington State FAS DPN website.

Lip-Philtrum Guides. The Lip-Philtrum Guides (Hemingway, 2024) are 5-point pictorial guides that were created by the FASD 4-Digit Code to accurately measure philtrum smoothness and upper lip thinness. The performance of 4-Digit Code Lip-Philtrum Guides have been extensively assessed and validated (Astley, 2013). The Lip-Philtrum Guide reflects the full range (or normal distribution) of lip thickness and philtrum depth that represent the general population; the Rank 3 picture reflects the population mean (or 50th percentile), where Ranks 1 and 5 reflect the extreme ends of the normal curve, at more than the 2.5th percentile and less than 97.5th percentile (Hemingway, 2024). The Lip-Philtrum Guides should be used by medical

professionals who have been trained with the 4-Digit Diagnostic Code. The medical doctor on the clinical evaluation team should select the Guide that best matches the phenotype of the patient's race(s), including thickness of lip. Each Guide gives pictural reference to each rank (Figure 6), as well as detailed Lip-Philtrum Guide Tables printed on the backside of each Guide (Figure 7). Additional guidelines are provided on the Washington State FAS DPN website.

Training at the UW FAS DPN Clinic

The training clinic at the UW FAS DPN is staffed by an interdisciplinary team which includes the clinic director, (who is also an epidemiologist, clinical researcher, and public health professional), pediatrician, psychologist, speech-language pathologist, and occupational therapist. An important note about this clinic is that the medical doctors who serve on the interdisciplinary team are pediatric certified, though use of the 4-Digit Code is not limited to children and FASDs are not only diagnosable by a pediatrician; having exclusively pediatric certified medical doctors is idiosyncratic of the UW FAS DPN clinic specifically.

In addition to the clinical team, the UW FAS DPN serves as a training and education center for professionals worldwide (FAS DPN Website, [Tableau](#) offers one-day or two-day trainings for professionals in person or by Zoom to learn an overview of current assessment, diagnostic and treatment strategies for the full spectrum of fetal alcohol disorders). The one-day training, which is provided to students and professionals alike at no cost, is offered weekly on Fridays at the UW FAS DPN and begins with a didactic lecture followed by direct observation of two diagnostic evaluations at the clinic. This training is targeted to community health and social service professionals and over 10,000 professionals have attended this training over the past 33 years (Hemingway, 2024). Participants learn what FAS is, how it is diagnosed, who benefits from a diagnostic evaluation, what services the UW FAS DPN provides and how to utilize them,

and what their role is in the referral, diagnostic and service provision process for these patients and their families (Hemingway, 2024).

The two-day training is conducted monthly for interdisciplinary clinical teams (or individual clinical team members) seeking to establish a FASD Diagnostic Clinic in their community. Trainees first complete the FASD 4-Digit Code Online Course. They are then introduced to the interdisciplinary approach to FASD diagnosis using the FASD 4-Digit Diagnostic Code via didactic lecture on the first day, with the second day spent observing of two FASD diagnostic evaluations conducted by the UW FAS DPN interdisciplinary diagnostic team using the FASD 4-Digit Diagnostic Code (Hemingway, 2024). The clinical teams learn how to conduct an interdisciplinary clinic using the FASD 4-Digit Diagnostic Code (Hemingway, 2024). Over 150 clinical teams and thousands of clinicians have been trained worldwide (Hemingway, 2024).

In addition to the two in-person training options, the Washington State FAS DPN website offers the FASD 4-Digit Code Online Course for professionals serving on interdisciplinary FASD diagnostic teams at no cost and self-paced. This course provides instruction on how to use the FASD 4-Digit Diagnostic Code. To date, over 3,000 professionals from 62 countries have completed the FASD 4-Digit Code Online Course (Hemingway, 2024).

Purpose of the Current Study

The literature documents the complex neurodevelopmental, educational, and behavioral needs of children with FASDs; however, there remains a critical gap in understanding how these needs are addressed within the special education system IEPs. Although children with FASDs often experience significant academic and social-emotional challenges, FASD is not recognized as a standalone eligibility category under the Individuals with Disabilities Education Act (IDEA;

IDEA, 2004; U.S. Department of Education, 2018). Consequently, children with PAE may be underserved or inappropriately supported, particularly when an FASD diagnosis has not been made or disclosed. Although research has documented high rates of comorbid conditions such as ADHD and learning disabilities among students with FASDs, far less is known about the extent to which clinical diagnostic findings and recommendations are reflected in school-based IEPs. Disparities in identification and service provision across race, gender, geographic region, and home placement further raise concerns about inequities in eligibility determination and access to appropriate supports (Daniel & Wang, 2023; Grindal et al., 2019; Guy et al., 2022; Moore et al., 2024; Platt & Gephart, 2022; Shifrer et al., 2011; Suhrheinrich et al., 2021; Walters, 2018; Zorc et al., 2013).

The purpose of the current study was to examine the extent to which recommendations from clinical diagnostic evaluations for children with FASDs align with, or differ from, the special education services documented in a child's IEP. Specifically, this study investigated the prevalence of preexisting IEPs among children receiving a FASD diagnostic evaluation at the UW FAS DPN clinic, as well as the special education eligibility categories under which these students are served, and what needs are captured by each evaluation. These questions address whether children had already met eligibility criteria for special education—and under which categories—based on demonstrated academic and social-emotional needs prior to receiving a formal FASD diagnosis. Prior research suggests that many children with FASDs experience significant functional impairment without being formally diagnosed; for example, Chasnoff et al. (2015) found that over 80% of children meeting criteria for FASD in a clinical sample had not previously received an FASD diagnosis. Given the symptom overlap between FASDs and other neurodevelopmental conditions, students without an FASD diagnosis may qualify for special

education services under alternative eligibility categories, such as Autism or Intellectual Disability.

Building on prior research and clinical practice, this study further examined the match or mismatch between clinical recommendations for interventions and services and students' existing educational programming. By comparing clinical evaluation reports from the UW FAS DPN clinic with school-based IEP documentation, the study aimed to identify gaps and opportunities for improvement in special education service delivery for children with FASDs. In addition, the study explored whether demographic variables were associated with patterns of service alignment or discrepancy. By analyzing records across clinical and educational contexts, this study seeks to generate practical, actionable knowledge for school psychologists and special education teams. Improving the alignment and responsiveness of IEPs for students with FASDs is essential not only for legal compliance, but also for ensuring that these students receive supports that adequately address their complex learning and behavioral needs (Flannigan et al., 2022; Millar et al., 2017; Riggie & Xu, 2013). The following research questions guide this study:

Research Question 1 (RQ1)

What proportion of patients had a preexisting IEP?

Many patients who are referred to the FAS DPN demonstrate ongoing academic and behavioral concerns and may already receive specialized support through an IEP to address documented learning, attention, or social-emotional challenges. It was hypothesized that over 50% of the study patients would have a preexisting IEP, given that many patients are evaluated at the FAS DPN clinic with previously diagnosed challenges in school.

Research Question 2 (RQ2)

Did the prevalence of a preexisting IEP vary by caregiver status, race, sex assigned at birth, and homeschool status?

Exploring descriptive variables provides an analysis of potential relationships between demographic variables and the likelihood that a patient has an IEP when they are evaluated at the FAS DPN clinic, specifically the geographic location of the patient's school district, caregiver status, sex assigned at birth, and public or private school enrollment versus homeschool enrollment status. It was hypothesized that patients who were in a foster care placement, patients who were non-white, patients who were female, and patients who were homeschooled would be less likely to have a preexisting IEP.

Research Question 3 (RQ3)

Among those with a preexisting IEP, what was the prevalence of each IEP eligibility category?

Given that FASD is not a disability recognized by IDEA, it was hypothesized that of the patients with a preexisting IEP, Other Health Impaired, Specific Learning Disability, and Emotional/Behavioral Disturbance would be the most common special education eligibility categories represented, given symptom and challenge overlaps with these disability eligibility categories. There is extensive research that supports the common overlap of symptoms of FASDs with other disabilities (Albert et al., 2021; Flannigan et al., 2022; Khoury & Milligan, 2019; Kurth et al., 2022; Mattson, Crocker & Nguyen, 2011; McDougall et al., 2020).

Research Question 4 (RQ4)

How often did the FAS DPN team recommend a change in the patient's preexisting IEP eligibility category?

It was hypothesized that patients at the more severe end of the FASD spectrum (FAS and SE/AE) would have the highest prevalence of IEP eligibility category disagreement, with the clinic suggesting a change in eligibility category. Children with more severe presentations of an FASD (e.g., FAS and SE/AE) exhibit complex neurodevelopmental and behavioral profiles that may go beyond what is captured by their IEP eligibility category (Kodituwakku & Kodituwakku, 2011; Petrenko, Pandolfino & Robinson, 2017).

Research Question 5 (RQ5)

To what extent did existing IEPs match the needs of the patient as determined by the FAS DPN clinical team (i.e., did the IEP specifically target the domains of need)?

It was hypothesized that students with ND/AE would be more likely than patients with FAS or SE/AE to have IEPs that do not match their needs, leading to poorer alignment between clinical needs and IEP services. Individuals with ND/AE may present with more subtle or less outwardly apparent neurodevelopmental impairments compared to those with FAS or SE/AE, given the severity of impact on brain function, which can make accurate school identification and categorization of educational needs more challenging (Chasnoff, Wells & King, 2015; Kodituwakku & Kodituwakku, 2011; Petrenko, Pandolfino & Robinson, 2017).

To build on quantitative exploration of the data, and to gain deeper insight into how clinical recommendations compare to educational documentation and service provision, the following qualitative research question was developed to explore specific services and accommodations provided within a patient's existing IEP:

Research Question 6 (RQ6)

How well do recommendations in the clinical report match the documented needs of the child in their IEP?

It was hypothesized that clinical diagnostic reports from the FAS DPN would demonstrate greater specificity in documenting clinically identified functional needs (e.g., fine motor functioning, sensory processing) than students' IEPs, resulting in measurable misalignment between clinical recommendations and school-based services and accommodations. Specifically, it was expected that IEPs would be less likely to explicitly name these functional deficits or to include corresponding targeted services (e.g., occupational therapy). Examining instances of misalignment—such as when a clinical report recommends occupational therapy due to demonstrated fine and gross motor deficits, but the IEP does not include OT as a related service—allows for a contextualized, document-embedded analysis of alignment and gaps between clinical recommendations and educational documentation (Eldh et al., 2020).

Chapter 3: Method

Study Context

As previously discussed, the UW FAS DPN clinic is located at the Institute on Human Development and Disability clinic at the University of Washington. To request an evaluation at the clinic, caregivers or patients over the age of 18 complete and submit a questionnaire called the New Patient Information Form (NPIF). This form documents the patient's developmental history as well as caregivers' concerns (Hemingway, 2024). When the completed NPIF is received by the clinic, the Clinic Director reviews the form and sends a letter informing the family of the status of the request and when they can expect the Clinic Coordinator to reach out to schedule an appointment (Hemingway, 2024). Patients with a confirmed PAE under the age of 22 years are eligible to be evaluated at the clinic. Before a patient's appointment is scheduled at the clinic, past records are requested with patient consent. These records include copies of previous school, medical, and psychological evaluations. Included in the school records are IEPs, behavior intervention plans (BIP), report cards, and prior evaluation documentation as early as Birth-to-Three services up to current. The UW FAS DPN dataset and patient records are representative of all information and records received by the time of a patient's evaluation at the clinic.

Documents for Comparison

The focus of interest on educational implications of an interdisciplinary evaluation and diagnosis of FASD leads the researcher to examine the school records available to the clinic when the patient is evaluated. This study compared two primary sources of documentation related to the educational needs of children with FASDs: (1) school-based IEPs, and (2) clinical recommendations embedded in the diagnostic evaluation reports from the UW FAS DPN clinic.

Both documents are designed to identify a child's unique learning and developmental needs. Similarly, both documents provide information specific to the interventions, accommodations, and related services that address the identified needs of the child. However, these documents originate from different systems—educational and clinical—and thus differ in their language, scope, and focus. IEPs are mandated to include clearly defined, measurable goals to address the educational needs of children with disabilities who are eligible for special education, ensuring that progress can be monitored and evaluated (IDEA, 2004). In contrast, a diagnostic evaluation report from the UW FAS DPN offers recommendations for interventions and accommodations but lack the explicit articulation of goals and measurable outcomes. This difference reflects the distinct purposes of each document: IEPs are designed to serve as actionable, progress-monitoring tools within the educational context, whereas clinical reports provide broader, diagnostic insights and guidance for individualized intervention.

Study Population

Records were intentionally selected from patients who were evaluated and diagnosed at the UW FAS DPN clinic between 2021-2024, representing a four-year sample. Approximately 70 patients are evaluated every year at the clinic. The UW FAS DPN collects records through an intake process that gathers questionnaire data, medical records, adoption records (if applicable), educational records (if applicable), and prior evaluation reports (if applicable). This data collection is convenience data because whatever families/caregivers bring to the clinic or sign releases of information for is the only information that the clinic has access to. Inclusion and exclusion criteria were implemented to aid in the organization and meaningfulness of the data analysis procedure.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were established to ensure that the sample was appropriate for the study aims and that participants could be meaningfully compared across educational and diagnostic variables.

Inclusion Criteria

1. Evaluated at UW FAS DPN clinic from 2021 through 2024.
2. All races/ethnic groups
3. Both sexes assigned at birth
4. WA residents
5. 8-18 years of age on date of diagnosis

Exclusion Criteria

1. Did not consent for use of data for research
2. Down's syndrome
3. ASD

Rationale for Inclusion/Exclusion Criteria. The decision to exclude younger children or adults who get a later-in-life diagnosis of a fetal alcohol spectrum disorder is twofold. First, there are developmental and psychometric limitations when evaluating a child younger than eight years old (Albert et al., 2021; Burgess et al., 2025). Developmental limitations include cognitive, language, and self-regulation skills that impact attention and stamina, abstract and conceptual understanding, behavior regulation (Thompson et al., 2018; Visser et al., 2012). Various psychometric limitations also impact the ability to conduct a comprehensive evaluation of younger children, including domains that are not assessable (such as executive functioning, academic achievement, and higher-order language processing), limited normative data with interpretable confidence intervals, and test reliability and validity for stable and predictive scores

over time (Howard & Melhuish, 2017; Tenorio, Campos & Karmiloff-Smith, 2014). Ultimately, comprehensive evaluations with children younger than eight years old are limited because of fewer reliable assessment tools normed for these ages and less stable and predictive performances and scores, especially given the reliance on observation or parent/teacher report, further limiting objectivity and comprehensiveness.

Secondly, the decision to exclude adults past the age of 18 is due to the possibility that most patients will no longer be in traditional K-12 school anymore. Because this study aims to examine a patient's clinical diagnostic report to compare with an existing IEP, including adults beyond the age of traditional public-school attendance would not provide information relevant to the study. Under IDEA, public schools are required to provide special education services only up to age 21 (IDEA, 2004), though not all students with disabilities stay in school that long. For example, once an individual becomes 18-years-old, their educational status may change due to graduating 12th grade or leaving school altogether (i.e., "dropping out"). Any evaluations that are conducted post-high school are no longer part of K-12 educational systems and thus fall under different service systems, such as college disability services, which do not use the same IEP process and do not follow federal law under IDEA for special education services (IDEA, 2004). Demographic information including age, gender identity, diagnosis, race/ethnicity, home placements, school changes, preexisting ADHD diagnosis, and geographic region were reported.

Individuals with preexisting autism or Down syndrome diagnoses were excluded from the study due to the substantial overlap in neurodevelopmental, cognitive, adaptive, and behavioral characteristics associated with these conditions. Including these populations may have made it more difficult to determine whether educational needs, IEP services, and clinical recommendations were specifically related to FASD rather than another co-occurring

developmental condition. For example, both ASD and Down syndrome are independently associated with difficulties in executive functioning, language, adaptive behavior, sensory processing, social communication, and intellectual functioning. Because the purpose of this study was to examine the alignment between FASD-related clinical recommendations and school-based educational planning, excluding participants with ASD or Down syndrome allowed for a clearer interpretation of the educational and functional profile uniquely associated with FASD. Although co-occurring ASD and genetic syndromes are important considerations in clinical practice, these conditions were excluded in the current study to increase the interpretability of findings related specifically to FASD.

Ethical Guidelines

This study adheres to the ethical guidelines for conducting research with human subjects, as outlined by the APA and the University of Washington Institutional Review Board (IRB). Given the sensitive nature of educational and clinical records for children, careful attention is given to protecting the confidentiality and dignity of all individuals whose data are included. The research involves a secondary records review, and all data are de-identified to prevent the possibility of re-identification. In compliance with ethical standards, only information that is necessary to address the research questions were extracted. No data was used that could compromise the privacy, rights, or well-being of the individual children who are represented in the study. Furthermore, the study minimizes risk by using secure data storage, limiting access to approved personnel, and following all protocols approved by the IRB.

HIPAA-Compliance and Legal Privacy

To ensure HIPAA compliance and protect the privacy of all individuals whose records are included in this study, and in accordance with the existing University of Washington IRB for the

clinic and all research conducted with clinical files, all data was securely stored on a HIPAA-compliant OneDrive account provided through the UW. All study procedures, including data security and privacy protections, have been approved by the existing IRB through Dr. Susan (Astley) Hemingway. No data were downloaded onto personal and non-secured devices. Access to the data is strictly limited to the clinical director, clinical coordinator, and the student researcher. Prior to conducting statistical analyses, all patient information was de-identified by assigning a unique study identification number to each record, thereby removing any direct identifiers and ensuring that no data can be traced back to individual patients. This approach aligns with federal privacy regulations and institutional guidelines for the handling of protected health information.

NASP Ethical Standards

As part of the National Association of School Psychologists Professional Standards, including the Principles for Professional Ethics, school psychology graduate students and credentialed professionals are held to ethical standards when conducting research (NASP, 2020). In particular, standards IV.5.1 (Conducting Research) and IV.5.2 (Protecting the Rights of Research Participants) address the importance of ethical and professional conduct for school psychologists when contributing to the field of school psychology through participating in, conducting, and disseminating research (NASP, 2020). The researcher adhered to these ethical and professional standards when conducting the secondary data analysis for this dissertation study.

Measures

The current study incorporates both quantitative and qualitative measures to examine the alignment between clinical diagnostic recommendations and services. Quantitative variables

include diagnostic outcomes, IEP status, demographic characteristics, and indicators of environmental stability, which were analyzed to assess patterns and predictors of service alignment. Qualitative data were drawn from narrative excerpts in clinical reports and IEPs, focusing on recommended and implemented services, supports, and accommodations. A structured coding matrix and codebook guided the qualitative analysis, with coded data organized into visual displays to identify alignment themes and potential contributing factors. Together, these measures provide a comprehensive framework for understanding how clinical recommendations are reflected—or missing—in special education documentation and support.

Quantitative Measures

Independent variables included demographic, diagnostic, and contextual characteristics hypothesized to influence educational service provision and alignment, including age, sex assigned at birth, race/ethnicity, caregiver status, geographic region, ADHD diagnosis, FASD diagnostic classification, 4-Digit Diagnostic Code, number of home placements, and number of school district changes. Dependent variables included the presence of a preexisting IEP, IEP eligibility category, related services, transition planning, and the degree of alignment between clinical recommendations and school-based programming. Alignment variables included whether the clinic recommended changes to eligibility category, occupational therapy, speech-language services, accommodations, or other educational supports. Certain variables related to education, such as IEP eligibility category and related services, functioned as both dependent and independent variables depending on the research question being examined.

For RQ1, the dependent variable was the presence of a preexisting IEP (yes/no), and the independent variable was diagnostic classification (FAS, SE/AE, and ND/AE). For RQ2, the dependent variable remained the presence of a preexisting IEP, and the independent variables

included sex assigned at birth, race/ethnicity, caregiver status, geographic region, homeschooled status, and foster care status. For RQ3, the dependent variable was IEP eligibility category, and the independent variable was FASD diagnostic group. For RQ4, the dependent variable was agreement between the clinic recommendation and the existing IEP eligibility category, and the independent variables included diagnostic group and CNS rank as reflected in the 4-Digit Diagnostic Code severity level. Finally, for RQ5, the dependent variable was the degree of match or mismatch between the IEP and the clinical recommendations, and the independent variable was diagnostic group.

The 4-Digit Diagnostic Code (Astley, 2024) has already been discussed and is a validated diagnostic system that demonstrates strong inter-rater reliability when used by trained clinical teams (Astley, 2013). The diagnostic categories used in this study are based on empirically supported diagnostic criteria (Chudley et al., 2005), contributing to strong content and construct validity. IEPs are derived from federally mandated procedures under IDEA (2004), ensuring consistent documentation across educational contexts. Taken together, these standardized and legally defined measures support the reliability and validity of the variables used to assess alignment between clinical diagnostic recommendations and school-based educational programming.

Alignment of the IEP with clinical report were operationalized by coding whether the diagnostic report includes recommendations for changes to educational programming. These may include the addition or removal of accommodations, related services (e.g., occupational therapy, speech-language services), and specific academic or behavioral interventions. Descriptive variables included sex assigned at birth (female or male), age at diagnosis (continuous variable), geographic region (rural or urban), and race/ethnicity (American Indian or

Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White, or Hispanic/Latinx or Multiracial). Guardian status was categorized as foster care, kinship care, adopted, or biological parent(s). Contextual variables related to environmental and educational stability included the number of home placements and the number of changes in school district attendance. These variables were analyzed to explore patterns of service alignment and potential moderating influences on the consistency of educational support for children with FASD.

Qualitative Measures

Qualitative data were derived from document excerpts within each participant's clinical diagnostic report and corresponding IEP, focusing on narrative elements related to recommended interventions, services, accommodations, and disability eligibility determination. The units of analysis include line-by-line excerpts containing clinical recommendations and educational content relevant to special education services and educational support. A structured coding matrix was developed to guide the qualitative analysis (Table 1). This matrix used deductive codes based on pre-established categories. All codes are defined in the codebook (Table 2) and were applied systematically across the dataset. To support analysis and interpretation, coded data were organized into data visual displays, allowing for comparison between clinical recommendations and IEP content across cases. These displays were used to identify themes of alignment or misalignment and to explore contextual factors that may be contributing to the discrepancies. All qualitative analysis were conducted in a secure location, with excerpts de-identified and linked only by unique participant IDs.

Research Design

There was a unique opportunity to investigate educational outcomes for students with FASDs through a secondary analysis of preexisting data from a diagnostic clinic, which includes clinical and educational documents for comparison. The present research design was a retrospective observational study using existing medical and educational records. This design allows for the investigation of alignment between preexisting IEPs and the identified needs of children with FASDs in interdisciplinary clinical diagnostic reports from the UW FAS DPN.

By combining quantitative and qualitative approaches, the findings are supported by objective metrics (e.g., proportions of addressed needs in an IEP) and qualitative context (e.g., examples of mismatch with clinical recommendations and the interventions and services written in a child's IEP). A quantitative analysis of the preexisting data (explained further in Data Analysis) enabled the researcher to make comparisons between the identified needs of a student from the clinical diagnostic report and the support and interventions and services as outlined in preexisting IEPs. Furthermore, using quantitative analysis facilitated the identification of gaps or discrepancies between clinical reports and IEPs (e.g., percentage of needs explicitly addressed in the IEP). To further explore the research questions using a qualitative analysis approach with the secondary data, the researcher explored how needs are described in clinical reports versus IEPs, including highlighting the nuanced or implicit supports that are not easily quantifiable from the data. This qualitative approach provided the researcher with the ability to capture subjective aspects of the documents/data. In summary, a secondary analysis for the proposed study will also facilitate cross-case comparisons (e.g., across demographic groups such as race, gender, caregiver status) to identify trends or disparities in the differences already present between IEPs and clinical reports. This approach provided insights for the need to improve collaboration

between clinical teams and school teams when considering a child's diagnosis of FASD and additional areas of support that may need to be addressed or changed in a child's IEP.

Procedure

This study utilized a secondary analysis of existing records obtained from the UW FAS DPN clinic. All data were de-identified prior to analysis and assigned a unique participant identification number to protect confidentiality. Quantitative and qualitative data, including diagnostic information, demographic variables, and IEP content, were extracted and entered manually into a secure, password-protected Microsoft OneDrive account provided by UW and the clinic. All statistical analyses were conducted using SPSS, with output files immediately uploaded to the secured OneDrive and permanently deleted from the researcher's local computer. No data were stored on the device's desktop, internal hard drive, or any unsecured storage locations at any time. Line-by-line coding of relevant excerpts from clinical evaluation reports and IEPs were conducted in a secure environment, using only the unique IDs to maintain patients' anonymity. All coding, data entry, and analysis took place in a private location to ensure compliance with ethical standards for handling sensitive and private health information. These procedures are designed to ensure rigorous data integrity while adhering to all UW and legal requirements for the protection of patients' privacy and confidentiality, as defined by HIPAA and the IRB.

Data Analysis

The data analyses for this study were designed to examine the alignment between clinical diagnostic recommendations and school-based IEP documentation for children with FASDs and to explore factors that may be associated with misalignment. This study incorporates both quantitative and qualitative data sources to strengthen the comprehensiveness and contextual

relevance of the findings. The quantitative data—such as frequencies of special education eligibility categories, presence of preexisting IEPs, diagnostic group membership, and demographic variables—allow for statistical analysis of the data. The qualitative data are derived from document review, including narrative descriptions within IEPs and clinical reports. These data provide critical insight into the specificity and relevance of services and accommodations, as well as areas where clinical recommendations are suggesting revisions to a child’s IEP based on the evaluation conducted at the clinic. Integrating both forms of data enhances the ability to assess not only whether students with FASDs are identified and served through special education, but also how their needs are – or are not – being addressed. The use of both quantitative and qualitative document data contributes to a richer, more holistic understanding of the challenges and opportunities in supporting students with FASDs in school settings when additional clinical information is available.

Quantitative Analysis

Quantitative data were analyzed using descriptive and inferential statistical techniques. First, descriptive statistics (means, SDs, proportions) were computed for all variables to summarize demographic characteristics, diagnostic categories, and educational service provision. These descriptive statistics provided an overview of the sample, including distributions by sex, race/ethnicity, geographic region of the patient’s school, adoption status, number of home placements, and school district changes. To examine the association between diagnostic group and IEP match status, diagnostic categories were collapsed into two groups (ND/AE vs. combined FAS and SE/AE) to accommodate small cell sizes. This resulted in a 2×2 table. Given the expected small cell counts, Fisher’s Exact Test was selected instead of chi-square, given the violation of chi-square assumptions related to expected cell counts. Because the primary

variables of interest were categorical, assumptions of normality and homoscedasticity were not required. Accuracy of data entry was ensured through systematic data cleaning and verification procedures. All variables were reviewed for completeness and plausibility, including checks for out-of-range values, missing data patterns, and inconsistencies across related variables. In addition, a subset of cases (30%) was randomly selected and double-checked against original source records to assess data entry accuracy. Discrepancies were identified and corrected prior to analysis. All quantitative analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 30.0 for Mac.

Qualitative Analysis

To analyze the qualitative data drawn from a patient's IEP and clinical documents, an *a priori* deductive codebook was developed based on the research questions, existing literature, and special education frameworks (e.g., IDEA eligibility criteria and IEP requirements). Codes were created to organize information related to IEP eligibility classification, alignment or discrepancy with clinical recommendations, specificity of services and accommodations, and indicators of educational need that were either addressed or omitted (Table 2). Operational definitions for each code to support consistent application for each student are found within codebook.

The patients who meet criteria for inclusion in the study was given unique identification numbers to maintain confidentiality and HIPPA compliance when completing the data tables. The first step was to separate the data based on document source – the IEP report and the clinical diagnostic report. Then, the researcher read and re-read educational interventions, accommodations, goals, delivery of service minutes, and pertinent qualitative information provided in summaries and notes within a patient's IEP line-by-line. These were entered into the

database and assigned relevant codes based on the *a priori* codebook. These data and codes guided data entry into the qualitative database. The researcher then read and re-read the patient's clinical report line-by-line, specifically in the education section of the clinical report that details whether the clinic agrees with existing IEP supports and eligibility, suggests accommodations and examples of implementation, interventions, and services, and suggests additional testing or changes in services depending on evaluation results. These data were again entered into the qualitative database and coded according to the *a priori* codes defined in the codebook.

All documents were reviewed and coded manually, with codes applied directly to relevant excerpts in both IEPs and clinic reports. This process allows for systematic comparison across cases and enables the identification of patterns and discrepancies in how educational needs are documented and addressed. Because the coding approach is deductive, data were analyzed within a structured framework and organized with data displays. Coded results were synthesized to address the research question and hypotheses that guided data analysis in Chapter 5.

Qualitative Case Selection. To address Research Question 6, a qualitative document analysis was conducted using a purposeful, criterion-based sampling strategy. This sampling strategy illuminates patterns identified in quantitative analyses and provides contextualized, information-rich examples of key findings (Patton, 2015). Because the goal of Research Question 6 is to understand how alignment or misalignment occurs at the document level, rather than to estimate prevalence, purposeful sampling was selected as the most methodologically appropriate approach. Cases were drawn from the 45 patients in the dataset who had both an IEP and a clinical evaluation report. Guided by both qualitative standards and results from the quantitative analyses in Research Questions 1–5, three sampling groups were constructed to

illustrate the spectrum of alignment between clinical recommendations and educational documentation.

High-Match Cases ($n = 5$) reflected strong alignment in the quantitative analyses. Selecting these cases allowed for examination of what effective integration of clinical findings looks like in practice. *Low-/No-Match Cases* ($n = 5$) demonstrated limited or no alignment in the quantitative analyses (e.g., few or no sensory-related support despite documented deficits). Selecting these cases provided insight into the systemic, procedural, or contextual factors contributing to the misalignment patterns identified statistically. *Differences in Subpopulations Cases* ($n = 5$) were selected based on variables that emerged as meaningful in the quantitative analyses, including presence of dual diagnosis of ADHD, sex, district characteristics, and domain-specific recommendations. These cases allowed for deeper exploration of how alignment patterns vary across demographic variables, IEP eligibility categories, and district contexts. A total sample of 15 cases was selected to balance depth with representation of key quantitative patterns, consistent with recommended sample sizes for qualitative document analysis and comparative case studies. This sampling approach ensured that the qualitative findings meaningfully extended and contextualized the quantitative results.

Design Limitations and Validity

A limitation in this study design is incomplete records. Missing data can lead to biased findings if records are incomplete or missing important diagnostic, educational, or developmental information (Ibrahim, Chu & Chen, 2012). The primary data sources—clinical diagnostic reports from the UW FAS DPN clinic and IEPs—offer valuable insight into diagnoses and educational support for children with FASDs, but they do not always capture the full scope of a child’s educational experience or support needs. For example, there may be instances in

which a child had an IEP at their school, but this document was not provided to the diagnostic clinic, leading to an underrepresentation of educational supports in the dataset. As a result, the absence of an IEP in the clinic records cannot be assumed to indicate the complete absence of an IEP in practice. The clinic coordinator and specialist and UW FAS DPN make every effort possible to obtain school records by the time a patient is seen at the clinic for an evaluation, and even still, there are patients whose IEPs and other school records are incomplete or missing at the time of their evaluation.

Limitations on the day of the patient's evaluation at the UW FAS DPN clinic is another potential threat to the validity of the study. The diagnostic reports from the clinic capture a single assessment day over the course of four hours. Howieson (2019) highlights that standardized procedures are often different from real-world activities, potentially limiting the environmental validity of assessments, given the 'optimal' conditions of no other peers or visual and auditory distractions, regularly offered breaks and snacks, and 1:1 testing conditions. Furthermore, temporary factors such as fatigue, stress, or anxiety can influence an individual's performance during evaluations (Jones et al., 2022). These considerations underscore the importance of interpreting assessment results within the context of both the testing environment and the individual's typical daily experiences.

Another factor relates to geographic variability in educational and clinical resources. Patients evaluated at the UW FAS DPN diagnostic clinic may live in a range of districts and regions of the state, some of which may have more limited access to special education services, qualified providers, and comprehensive evaluations. In these cases, the lack of identified supports or formal interventions in a child's IEP may reflect systemic or structural limitations rather than the school-based team's ability to identify a child's individual needs and provide

adequate support (Butterworth, Denham & Hestenes, 2024). Thus, regional differences could negatively impact interpretations of how well the IEP process is meeting the needs of children with FASD, particularly given access to services is not uniform across the sample.

A final limitation in this study design is the incomplete context provided by the available documentation. IEPs reflect a negotiated process between families and schools, and may not fully represent the entirety of concerns, requests, or professional recommendations made during that process. There are instances in which caregivers may have advocated for additional accommodations, services, or interventions that were ultimately not included in the finalized IEP. Conversely, providers and educators may have recommended certain supports that caregivers declined, and these decisions are not typically documented within the IEP itself. The dynamics between the key stakeholders in an IEP team may result in an incomplete picture of the child's actual support needs or the efforts made to address them, introducing another layer of complexity to the interpretation of findings (Sanderson & Rojas, 2023). Taken together, these limitations underscore the importance of interpreting the data with caution and acknowledging that formal documentation—though essential—is only one piece of the broader context in which educational and clinical decisions are made for children with FASD.

Chapter 4: Results

This chapter presents the quantitative and qualitative results of the study organized by research question. First, quantitative results addressing Research Questions 1 through 5 (RQ1–RQ5) are presented to examine the prevalence of preexisting individualized education programs (IEPs), demographic predictors of IEP identification, special education eligibility categories, and the degree of alignment between school-based IEP documentation and interdisciplinary clinical recommendations for children diagnosed with fetal alcohol spectrum disorders (FASDs). Second, qualitative results addressing Research Question 6 (RQ6) are presented to explore how clinical recommendations documented in interdisciplinary diagnostic reports are reflected in students' IEPs and to characterize patterns of match and mismatch between clinical and educational documentation.

Sociodemographics of the Study Population

Of the 246 patients evaluated for FASD from 2021-2024, 100 met the inclusion criteria. Twelve were excluded due to a preexisting diagnosis of ASD. Thus, 88 total patients were eligible for this study. Of the 88 patients, just over 50% were female ($n = 49$) and 44% were male ($n = 39$). Ten patients (11%) were homeschooled, with the remaining 78 patients (87%) attending school outside of the home. Fifty-one patients (58%) identified as non-White. Five patients (11%) were cared for by biological parents, 24 patients were adopted (53%), 11 patients (24%) were being cared for by a family member (kinship care), and 4 patients (9%) were in foster care. Table 3 provides expanded sociodemographic information about the patients in this study.

RQ1: What proportion of patients had a preexisting IEP?

It was hypothesized that the majority of patients (over 50%) would have a preexisting IEP, given that many were referred to the clinic following demonstrated challenges in school.

Across the full sample ($N = 88$), 45 patients (51%) had a preexisting IEP, while 43 patients (49%) did not. By diagnostic group, 67% of patients with fetal alcohol syndrome (FAS; 2 of 3) and 58% of patients with static encephalopathy/alcohol exposed (SE/AE; 35 of 60) had preexisting IEPs. In contrast, only 32% of patients with neurodevelopmental disorder/alcohol exposed (ND/AE; 8 of 25) had a preexisting IEP. Although the overall proportion of patients with IEPs (51%) narrowly met the hypothesized threshold, results varied substantially by diagnostic group. Patients with FAS and SE/AE were more likely to have IEPs, whereas those with ND/AE were considerably less likely to have one. Thus, hypothesis 1 was supported overall; however, rates of IEP identification differed substantially by diagnostic group (Table 4). Other sociodemographic variables by FASD diagnosis are highlighted in Table 3.

RQ2: Did the prevalence of a preexisting IEP vary by caregiver status, race, sex assigned at birth, and homeschool status?

The literature suggests that demographic and contextual factors may influence the likelihood of special education identification (Quinn & Madhoo, 2014; Rucklidge, 2010; Sullivan & Artiles 2011; Sullivan & Bal, 2013; Young et al., 2020). Accordingly, it was hypothesized that patients who were in foster care placements, patients who were non-White, patients who were female, and patients who were homeschooled would be less likely to have a preexisting IEP. Foster care status was not consistent with the hypothesis: children in foster care were more likely to have a preexisting IEP (80%; 4 of 5) compared to children not in foster care (49%; 41 of 83). In contrast, race, sex, and homeschool status aligned with predictions. Non-White patients were less likely to have an IEP (45%; 23 of 51) compared to White patients (59%; 22 of 37). Females were slightly less likely to have an IEP (47%; 23 of 49) compared to males (56%; 22 of 39). Finally, homeschooled children were much less likely to have an IEP (0%; 0 of

10) compared to their non-homeschooled peers (58%; 45 of 78). Thus, hypothesis 2 was partially supported: non-White patients, females, and homeschooled children were less likely to have IEPs as expected, but foster care patients were more likely to have IEPs (Table 5).

RQ3: Among those with a preexisting IEP, what was the prevalence of each IEP eligibility category?

Among the 45 patients with IEPs, the majority were classified under OHI (64%; n = 29), followed by SLD (13%; n = 6), Developmental/Intellectual Disability (9%; n = 4), and EBD (9%; n = 4). A small number were classified under Multiple Disabilities (4%; n = 2). No patients had IEPs under Autism Spectrum Disorder, Speech or Language Impairment, or other IDEA categories. These results indicate that OHI was by far the most common eligibility category, with SLD and EBD also represented, consistent with the hypothesis. However, the presence of Intellectual Disability at a rate equal to EBD identified an additional eligibility category that was not anticipated. It was hypothesized that, among patients with preexisting IEPs, the most common eligibility categories would be Other Health Impaired (OHI), Specific Learning Disability (SLD), and Emotional/Behavioral Disturbance (EBD), due to overlap in symptom presentation between these categories and FASD. Overall, hypothesis 3 was supported, although additional eligibility categories were observed (Table 6).

RQ4: How often did the FAS DPN team recommend a change in the patient's preexisting IEP eligibility category?

Across all patients with IEPs, 78% (n = 35) had clinic agreement with their IEP eligibility category, and 22% (n = 10) had clinic recommendations for change. Among diagnostic groups, 100% of FAS patients (2 of 2) had agreement in eligibility category (OHI), and no changes were recommended. For SE/AE patients, 77% (27 of 35) had agreement, and 23% (8 of 35) were

recommended for change. Six of the eight patients who were recommended to receive a change in category were to the category of OHI, and two of the eight patients were recommended to receive a change in category to Multiple Disabilities. For ND/AE patients, 75% (6 of 8) had agreement and 25% (2 of 8) were recommended for change; one patient was recommended for a change in category to OHI and the other patient was recommended for a change in category to Multiple Disabilities. It was hypothesized that patients at the more severe end of the FASD spectrum (FAS and SE/AE) would show the highest prevalence of disagreement between their IEP eligibility category and the clinic's recommended category. Contrary to the hypothesis, disagreement was not most prevalent among the FAS group; in fact, no FAS patients had discrepancies. Instead, disagreement was observed at similar rates for SE/AE and ND/AE patients (Table 7a).

It was further hypothesized that patients with the most severe CNS dysfunction (CNS Rank 3) would demonstrate the highest prevalence of IEP eligibility category disagreement. Across the 45 patients with IEPs, 78% (n = 35) showed agreement between school and clinic eligibility categories, and 22% (n = 10) had disagreements. Nearly all cases of disagreement occurred among patients with CNS Rank 3 (24%; 9 of 38), with only one case occurring in a CNS Rank 2 patient (14%; 1 of 7). No cases at CNS Rank 1 were available. These results provide further evidence that IEP–clinic disagreement was primarily concentrated among patients with the most severe CNS dysfunction (Table 7b).

RQ5: To what extent did existing IEPs match the needs of the patient as determined by the FAS DPN clinical team (i.e., did the IEP specifically target the domains of need)?

A Fisher's Exact Test was conducted to examine the association between diagnostic group (ND/AE vs. combined FAS and SE/AE) and IEP match status (match vs. mismatch)

consistent with the study's a priori hypothesis. Diagnostic groups were collapsed due to the small number of patients diagnosed with FAS, resulting in a 2×2 contingency table appropriate for Fisher's Exact Test. Results indicated a statistically significant association between diagnostic group and IEP match status ($p = .014$). It was hypothesized that patients with ND/AE would be more likely than patients with FAS or SE/AE to have IEPs that did not match their identified needs. Contrary to the stated hypothesis, patients in the ND/AE group were more likely to have IEPs that matched their identified needs (62%) compared to patients in the combined FAS and SE/AE group (16%). Patients in the FAS and SE/AE group were substantially more likely to have mismatched IEPs (83%) than patients with ND/AE (38%). These findings indicate that diagnostic group was meaningfully associated with whether a child's IEP aligned with clinically identified needs; however, the direction of the effect was opposite of what was hypothesized (Table 8a). Given the small sample size—particularly within the ND/AE group ($n = 8$)—these findings should be interpreted with caution. The observed association may be sensitive to small changes in cell counts.

To further characterize the nature of IEP alignment, mismatch was examined across three levels: (a) no mismatch (fully matched), (b) some mismatch (one area), and (c) high mismatch (two or more areas). Among patients in the FAS and SE/AE group, only 16% had fully matched IEPs, whereas nearly half (49%) demonstrated some mismatch and 35% demonstrated high mismatch. In contrast, 62% of patients with ND/AE had fully matched IEPs. When mismatch was present in the ND/AE group, it was less frequent overall, with 13% classified as having some mismatch and 25% classified as having high mismatch. Although inferential testing was not conducted for these expanded categories due to small cell sizes, this pattern suggests that mismatch among FAS and SE/AE patients was both more prevalent and more consistently

distributed across multiple areas, whereas ND/AE patients were more likely to fall at the extremes, either fully matched or more substantially mismatched (Table 8b).

An even further descriptive breakdown examined the specific types of clinical recommendations contributing to partial or full mismatch between clinical reports and IEPs (Table 9). Because the clinical team sometimes made multiple concurrent recommendations for a single patient, categories were not mutually exclusive. Within the FAS and SE/AE group, the most common sources of partial mismatch involved recommendations to add or change occupational therapy services (62%) and to add or revise transition planning (27%). Speech-language pathology changes were less frequent (11%). Additionally, in 22% of cases, the clinic team disagreed with the student's existing eligibility category for special education services. Among patients with ND/AE, partial mismatches were less frequent overall. Only 13% received recommendations related to occupational therapy changes, and no ND/AE patients received recommendations for speech-language services. Similar proportions of ND/AE and FAS/SE/AE patients received recommendations related to transition planning (25%), and clinic disagreement with eligibility category occurred at comparable rates across groups (25% ND/AE; 22% FAS and SE/AE).

Taken together, the quantitative findings revealed both the prevalence and heterogeneity of mismatch between interdisciplinary clinical recommendations and IEP documentation, with patterns varying by diagnostic group and by the level at which mismatch was examined. To address these gaps, the qualitative analysis corresponding to Research Question 6 examined the language, content, and framing of clinical diagnostic reports and IEPs to provide contextualized understanding of observed matches and mismatches (**RQ6: How well do recommendations in the clinical report match the documented needs of the child in their IEP?**).

All 45 patients with preexisting IEPs were initially analyzed to determine match or mismatch between clinical recommendations and corresponding educational documentation, as inclusion of both records was necessary to examine alignment. From there, 15 cases were purposefully selected to deepen the interpretation of findings from Research Questions 1–5 and to extend quantitative contrasts examined in RQ2 and RQ5 regarding IEP presence and level of clinical–school alignment across FASD diagnostic classifications. Cases were examined using three analytic lenses—High Match, Low-/No-Match, and Differences in Subpopulations (patterns observed within diagnostic groups). These lenses were not mutually exclusive; individual cases could contribute to multiple analytic themes depending on the dimension of alignment examined. By analyzing a smaller, diverse subset in depth, the qualitative results provided specificity regarding how alignment and mismatch manifested in practice, thereby strengthening interpretation of quantitative patterns observed across the full sample of 45 patients.

The *High-Match* cases illustrate conceptual alignment between interdisciplinary clinical recommendations and IEP-documented eligibility categories, service domains, and accommodations, including explicit correspondence in at least two of the following areas: (a) special education eligibility category, (b) identified domains of need, and (c) recommended or existing services and supports. Of the 45 patients with IEPs, 24% ($n = 11$) demonstrated high alignment between clinically identified needs and existing IEP services and accommodations. Five of these 11 cases were intentionally selected to examine high-match patterns in greater depth. The *Low-/No-Match* cases provide document-level evidence of the misalignment patterns identified in the quantitative analyses, including missing services, vague statements for services, and minimal (or no) representation of clinically identified deficits. Of the 45 patients with IEPs,

two-thirds demonstrated low-match ($n = 19$, 42%) or no-match ($n = 15$, 33%) alignment between clinically identified needs and existing IEP services and accommodations. Five of these 34 cases were intentionally selected to examine mismatch patterns in greater depth.

The *Differences in Subpopulations* cases allow for focused exploration of specific quantitative findings of interest, including comorbid ADHD diagnoses, occupational therapy or speech-language pathology recommendations due to missing services, sex assigned at birth, school district geographic variation. Of the 45 patients with IEPs, 84% ($n = 38$) had an ADHD diagnosis, 40% ($n = 14$) were missing related and ancillary services (i.e., occupational therapy or speech/language) identified by the clinical team as significant areas of deficit, 51% ($n = 23$) were female, and 29% ($n = 13$) were in a rural school district. Five total cases were chosen to represent these variables of interest.

Across the 15 selected cases, levels of alignment between interdisciplinary clinical recommendations and school-based educational programming varied substantially, paralleling the distribution of outcomes observed in RQ5. Some cases demonstrated full alignment, with consistent identification of disability categories and recommended supports across documents. Other cases exhibited partial or substantial mismatch, reflected in absent related services, insufficient accommodation of documented neurocognitive needs, or discrepancies between clinical recommendations and IEP content. Mismatch counts ranged from zero (full alignment) to multiple areas of misalignment. For the majority of cases (76%; $n = 34$), the interdisciplinary clinical team recommended some degree of educational service change, including additions of or modifications to OT, SLP services, transition planning, Section 504 Plans, or ongoing monitoring. These qualitative patterns parallel and contextualize the quantitative findings. To illustrate these patterns, de-identified excerpts from both FASD diagnostic reports and IEPs are

presented for each selected case. Quotations are labeled using numerical placeholders and are used to demonstrate how clinical needs are or are not reflected in IEP documentation. All quoted material is reproduced verbatim from source documents. Identifying information has been changed, with renaming all patients to PATIENT, all dates replaced with xx/xx/xxxx, and inserting bracketed descriptors to protect confidentiality. Misspellings present in original documents are indicated with *[sic]*.

Qualitative Results by Group

High Match

Eleven of the 45 patients (24%) with IEPs had high match between the clinic recommendations and their IEPs. In several cases, the IEP clearly reflected the specific neurodevelopmental needs identified in the interdisciplinary clinical evaluation, with explicit reference to functional domains and areas of deficit emphasized in the clinical report (e.g., executive functioning, adaptive behavior, sensory regulation). All five patients that are highlighted below had alignment on eligibility category for special education services.

- **Patient 7 was diagnosed at age 8 (4-Digit Code 1134), SE/AE**

The patient was referred to the FAS DPN clinic with an existing diagnosis of *Neurobehavioral Disorder, Alcohol-Exposed* and was seeking diagnostic clarification through a comprehensive interdisciplinary evaluation. At the time of evaluation, Patient 7's IEP included an "Educational Implications" section describing the functional impact of their diagnosis. The IEP explicitly identified challenges across multiple developmental domains, including memory, executive functioning, behavioral regulation, adaptive skills, communication, motor coordination, spatial awareness, and social interaction:

Students with Neurobehavioral Disorder: Alcohol exposed may have difficulty with memory, thinking skills, behavioral problems, difficulty with tasks of daily living (dressing/bathing), and may have difficulty interacting with other children. Student with developmental delays may have difficulty with controlled speech, difficulty controlling breathing and phonation, difficulty with balance, trouble with spatial awareness, difficulty holding and picking up items, and trouble with body awareness.

(IEP_007, p. 7)

Findings from the interdisciplinary clinical evaluation supported these documented areas of need. The FAS DPN clinical report identified sensory-motor challenges, executive functioning deficits, and difficulties with attention and impulsivity as significant barriers to educational access. Correspondingly, the clinical team recommended the continuation of occupational therapy services and additional supports targeting executive functioning that were:

An occupational therapist to support PATIENT's sensory-motor, sensory processing, and handwriting development should continue to be part of his IEP. The supports for his impairments in executive functioning, and attention and impulsivity are warranted as these constitute significant barriers to his access to educational curriculum.

(Clin_007, p. 18)

Although the language used in the IEP and clinical report was not identical, the two documents demonstrated strong conceptual alignment. Both identified overlapping domains of need—particularly sensory-motor functioning and executive control—and endorsed occupational therapy and related supports as essential components of the patient's educational programming.

- **Patient 14 was diagnosed at age 11 (4-Digit Diagnostic Code 1123), ND/AE**

Though he has made growth in many ways, he continues to have difficulties in the area of social/emotional/behavioral functioning (IEP_014, p. 3)

Curriculum and instruction will be primarily general education content. Specially-designed instruction will mirror PATIENT's general education setting to the degree that it most benefits him... SDI Recommendations: Written Language, Reading, Social/Emotional and/or Behavioral (IEP_014, p. 9)

Alignment in the clinical documentation was high, as results from testing indicated that current services in the patient's IEP addressing academic and social/behavioral supports should continue as documented. In this case, alignment was demonstrated through consistency across documents in both the identification of social/emotional/behavioral needs and the continuation of academic and behavioral supports without recommendation for modification:

Continue school special education services that include academic and social/behavioral supports. (Clin_014, p. 16)

Agreement on the patient's eligibility category in addition to the current services (academic, including written language, reading, and social/behavioral) identified in the patient's IEP indicate high match. No recommendations were made to change or add services for this patient.

- **Patient 16 was diagnosed at age 11 (4-Digit Diagnostic code 3233), SE/AE**

Patient 16's IEP included rationale for their eligibility for special education under the IDEA category "Other Health Impairment" that captures several domains of functioning which are impaired, including academics (reading, writing and math), as well as communication and social/emotional/behavioral skills. Despite the temporal gap between the school-based evaluation and the clinical assessment, this case demonstrated strong continuity in identified needs and

services. This patient's IEP included an amendment in which her special education teacher and SLP addressed the impact of the COVID-19 pandemic on the patient's IEP goals and accessibility to services:

Due to the global pandemic, COVID-19, school and therapy are access *[sic]* through virtual/remote learning. Asynchronous materials and resources have been available on the Schoology platform as well. PATIENT has been relatively inconsistent with her attendance in therapy since returning to school with a hybrid model.

(IEP_amendment_016, p. 6)

The FAS DPN clinical team agreed with the eligibility category and current services listed in the patient's evaluation (which took place over two years prior to the patient's appointment at the FAS DPN):

Continued support for learning as a student with "other health impairment" through an individualized education program (IEP) is recommended. This eligibility category continues to capture her disabilities, which represent significant barrier for her access to age-appropriate curriculum. Her IEP should provide appropriate accommodations and specialized instruction to support reading/literacy, motor development, speech sound production, adaptive skills, social skills, and social-emotional-behavioral regulation.

(Clin_016, p. 17)

An additional consideration for this patient's evaluation (beyond the impact of the pandemic) is to acknowledge that the patient was seen at FAS DPN nearly eight months before their triennial re-evaluation was due at their school; the clinical team specifically named accommodations and specialized instruction suggestions that aligned with needs that were already included in the patient's evaluation from two-and-a-half years prior. The clinical team evaluation provided

evidence through their testing that the areas of need already defined and supported in the patient's IEP were continued areas of challenge and require targeted support and specially designed instruction.

- **Patient 62 was diagnosed at age 12 (4-Digit Diagnostic Code 1124), ND/AE**

Patient 62's IEP and re-evaluation documents define their need for specially designed instruction in math and written language as well as an eligibility change to Health Impaired (from Specific Learning Disability) to best represent the impact of her ADHD on her learning:

Results of the current reevaluation indicate PATIENT continues to exhibit adverse impact in Written Language and Math. These challenges are likely stemming from legitimate underlying processing deficits manifesting in learning difficulties as described in her initial evaluation. Since her initial evaluation in 2020, PATIENT's parents report that she has received a diagnosis of ADHD. The disability category of Health Impairment is currently the most accurate category to describe her disability and this significantly impacts her ability to successfully access and make progress without specially designed instruction in Written Language and Math. (IEP_062, p. 16)

The clinical report reflected strong alignment with the supports and accommodations documented in the patient's IEP, with the interdisciplinary team explicitly affirming the adequacy of existing services:

PATIENT will continue to benefit from specialized instruction and appropriate accommodation through an individualized education plan (IEP) as student with 'Other Health Impairment.' Support for mathematics and English-Language Arts will continue to be important for CLIENT as she moves through school and demands on literacy

increase...She should continue to have appropriate accommodation for her challenges with attention and focus, and her challenges with verbal fluency. Those listed in her 2023 IEP appear appropriate. (Clin_062, p. 17)

This case highlights strong conceptual alignment between the FAS DPN clinical recommendations and IEP-documented services, demonstrating that appropriate educational supports were in place even in the absence of diagnostic-specific language.

- **Patient 72 was diagnosed at age 10 (4-Digit Diagnostic Code 2124), ND/AE**

In addition to specific goals and progress monitoring data, Patient 72's IEP includes service delivery frequency/dosage detailing their need for specially designed instruction in social and emotional behavior as well as OT as a supplementary aid and service:

PATIENT's disability impacts his progress in the general education curriculum, and he requires specially designed instruction in the areas of Behavior and Social/Emotional as well as the Supplementary Aid and Service of Occupational Therapy. (IEP_072, p. 7)

Behavior, 20 minutes / 4 times weekly; Social/Emotional, 10 minutes / 5 times weekly; Occupational Therapy, 20 minutes / 1 times monthly (IEP_072, p. 14)

Patient 72's IEP also provides a list of accommodations and modifications in order to successfully move toward attaining their identified annual goals:

Accessories & Equipment: Use of sensory/fidget items; Daily; All School Settings

Accessories & Equipment: Visual Aids; Daily; All School Settings

Environment/Setting: Freedom to move; movement breaks; Daily; All School Settings

Text-to-Speech; Daily; All School Settings

Frequent verbal reminders and visual cues to help identify and express feelings; Daily;
All School Settings (IEP_072, pp. 11-12)

These accommodations and specific services are of particular importance in demonstrating the alignment with the results of the clinical evaluation:

PATIENT will continue to benefit from specialized instruction and appropriate accommodation through an individualized education plan (IEP). Current support and accommodation for challenges with social-emotional-behavioral challenges should remain in place as should support from occupational therapy for sensory needs.

Handwriting accommodations including speech-to-text ... should also continue.

(Clin_072, p. 19)

High match is evident between the documented needs and supports from the patient's IEP and the FAS DPN clinical recommendations. The school-based triennial re-evaluation, conducted six months prior to the FAS DPN assessment, likely contributed to the strong conceptual alignment observed across documents, including consistent identification of social-emotional-behavioral needs, sensory supports, and occupational therapy services. Across high-match cases, documents demonstrated consistency in eligibility category, identified domains of need, and recommended services, despite variability in diagnostic terminology.

Low-/No-Match

The Low-/No-Match group represents patients whose needs were identified in the FAS DPN report and may be acknowledged in a patient's IEP but missing direct services. For instance, clinical reports frequently detailed multi-domain executive functioning impairments; however, corresponding IEP present levels sometimes utilized generalized statements such as "struggles with work completion," without explicit reference to underlying cognitive processes

affecting executive functioning and access to learning. Additionally, goals found in the IEPs within this group often targeted broad task completion or classroom behavior rather than the specific executive function mechanisms identified clinically. In some cases of mismatch, clinical recommendations were not at all reflected in IEP documentation. In these cases, clinical reports frequently identified significant neurocognitive challenges—particularly in executive functioning, memory, fine and gross motor, and sensory regulation—yet the corresponding IEPs contained limited or no reference to these domains.

In several instances, IEP present levels focused narrowly on academic performance or externalizing behaviors, while omitting underlying neurodevelopmental explanations emphasized in clinical evaluations. For example, clinical recommendations calling for explicit fine motor supports, environmental modifications, or increased monitoring were not consistently documented in IEP needs statements or goal rationales. IEP goals frequently focused on academic task completion (e.g., reading fluency, math computation) without explicit reference to executive functioning, sensory regulation, or other neurocognitive domains identified in clinical evaluations. These Low-/No-Match cases illustrate a mismatch between interdisciplinary diagnostic evaluation findings and recommendations, and the existing services and areas of need identified in a patient's IEP. In contrast to the high-match cases, these Low-/No-Match cases were characterized by limited or no alignment of clinically identified neurodevelopmental needs with IEP-documented services, goals, or eligibility determinations.

- **Patient 4 was diagnosed at age 10 (4-Digit Diagnostic Code 2134), SE/AE**

Patient 4 was seen at age 10 for a re-evaluation (patient previously was evaluated at age 5). At that time, Patient 4 was diagnosed with Neurobehavioral Disorder/Alcohol-Exposed. At this patient's re-evaluation, their brain rank rose to a "3" in the 4-Digit Diagnostic Code, which

elevated their diagnosis to Static Encephalopathy/Alcohol-Exposed. Patient 4's special education services were provided under the eligibility category of Specific Learning Disability in Mathematics and Written Expression. This patient also had a preexisting diagnosis of ADHD which was documented in their IEP. There were no related services or supplemental aids and services minutes in their IEP. This patient attended three different school districts from preschool to 5th grade, which is the grade they were currently in at the time of re-evaluation. Their IEP directly acknowledged prenatal exposure to substances, as well as the evaluation and diagnosis from the FAS DPN:

PATIENT has been diagnosed with ADHD and is taking medication which appears to be having a positive effect. Based on information received from his previous school, PATIENT's birth mother consumed alcohol and reportedly cocaine, heroin, cigarettes and methadone. PATIENT experienced neglect the first 10 weeks of his life and had multiple home placements until he was adopted by his current parents... A diagnosis of Neurobehavioral Disorder/Alcohol-Exposed was made by the Fetal Alcohol Syndrome Clinic at the UWMC on xx/xx/xxxx. For more Information regarding his medical history, please refer to the reports in his special services file. (IEP_004, p. 9)

The patient's performance on writing tasks administered during the clinical evaluation, there was a clear deficit in fine motor skills and writing with a pencil was particularly effortful for the patient, demonstrating an impact to their overall handwriting development:

PATIENT's Visual-Motor Integration (VMI) standard score was 45, which is below the 1st percentile for his age, placing his performance within the Very Low range.

Additionally, PATIENT's Motor Coordination standard score was 54 (<1st percentile),

and within the Very Low range. PATIENT received a standard score of 74 on Visual Perception (4th percentile). (Clin_004, p. 8).

The patient's IEP included one measurable goal for writing and did not address fine motor or handwriting challenges through specially designed instruction nor as a related or supplementary service:

By xx/xx/xxxx, when given a nonfiction writing topic PATIENT will write [*sic*] make a claim using at least two supporting details from the text and end with a conclusion improving written expression skills from 0 out of 5 attempts to 4 out of 5 attempts with no more than 2 prompts as measured by biweekly progress monitoring assessments.

(IEP_004, p.7)

The clinical team at FAS DPN provided specific service addition recommendations as well as a suggestion for a change in eligibility category to better capture the diagnoses of the patient:

We would recommend that an occupational therapist be added to his services with a focus on improved handwriting and fine motor coordination needed for academic activities. The IEP team may wish to consider whether a change in eligibility category to "other health impaired" which may better capture the range of disabilities he displays in the context of his attention-deficit/hyperactivity disorder, and his static encephalopathy/alcohol exposed. (Clin_004, p.16)

This case illustrates mismatch not through absence of academic support, but through the lack of services and eligibility alignment addressing the patient's fine motor and handwriting impairments, despite clear evidence as determined by the clinical evaluation. Notably, this patient's evaluation at their school was exactly one year prior to their appointment at the FAS DPN and would have just had their annual IEP meeting the same week they were re-evaluated;

however, their school-based triennial evaluation was still two years away. The clinical team made suggestions for an eligibility category change in addition to recommending occupational therapy to address handwriting and fine motor coordination.

- **Patient 11 was diagnosed at age 9 (4-Digit Diagnostic Code 1133), SE/AE**

Patient 11 represents a case of low match, in which eligibility category was consistent across documents, but multiple clinically identified domains of need were not reflected in the patient's IEP services or supports.

PATIENT will continue to benefit from specialized instructions and appropriate accommodations through an individualized education program (IEP) as a child with Other Health Impairments based on her fetal alcohol spectrum disorder. (Clin_011, p. 13)

Despite alignment on the clinical team and school team's determination of eligibility category for Patient 11, the clinical team recommendations indicate several missing domains of need and the associated services to address them:

Her IEP should include supports for academics, motor development, handwriting, social-emotional behavioral development, communication/social skills, and adaptive skills.

(Clin_011, p. 13)

Support in learning handwriting and exploration of keyboarding training and other strategies for improving handwriting efficiency are recommended. "Handwriting Without Tears" is one handwriting curriculum to consider. (Clin_011, p. 14)

Patient 11's IEP did not indicate specially designed instruction or supplementary support for motor development, handwriting, social skills, and adaptive skills. Additionally, the patient's IEP did not include a BIP that addresses their behavioral concerns:

... PATIENT's IEP should include a Behavioral Intervention Plan based on a functional behavioral analysis that is updated regularly. (Clin_011, p. 13)

Finally, the patient's clinical evaluation results indicated deficits in sensory processing that was not previously addressed in their IEP:

PATIENT processes sensory information in a different way. The team recommends in-class accommodations and a classroom consultation with an occupational therapist (OT). This can help in ongoing identification of resources and accommodations to minimize potentially negative effects of differences in sensory processing on classroom and social success. Consultation and accommodations are appropriate for all environments. (Clin_011, p. 13)

An important consideration for this case regards the timing of their FAS DPN evaluation and the patient's triennial re-evaluation, such that the patient's evaluation at FAS DPN was six days before the required triennial re-evaluation at their school. Because almost three years had passed from their previous school-based evaluation, it is possible that several areas of need identified by the FAS DPN team would have been captured in their school evaluation.

- **Patient 26 was diagnosed at age 9 (4-Digit Diagnostic Code 1133), SE/AE**

This patient's IEP included specially designed instruction in reading, writing, and math, as well as social/emotional and communication support. At the time of the patient's FAS DPN evaluation, their IEP eligibility category was determined to be Emotional Behavioral Disability. The patient's IEP was missing speech-language pathology and sensory accommodations, two areas determined to be significant areas of need for the patient after their clinical evaluation at FAS DPN:

Her IEP team could consider changing her eligibility category to “Other Health Impaired” or “Multiple Disabilities” to capture the range of challenges she experiences as a result of her fetal alcohol spectrum disorder (FASD). We strongly recommend inclusion of speech-language pathology supports as part of her IEP to address concerns with communication and social interaction. This should include both specialized instruction in specific skills along with development of compensatory strategies to address the impact of her slower language-processing rate and to limit its impact on her academic and social development. (Clin_026, pp. 17-18)

Sensory accommodations are also recommended. Examples are a “wobble pad,” weighted lap pillow, and/or headphones to be used during the school day or in homework sessions. Modifications of the classroom environment may be useful, such as a “quiet office” space to assist in focusing at school. Recess is an important chance for movement, which should never be eliminated as a classroom discipline strategy. Scheduled “down time” in a quieter, calmer space can help. The occupational therapist (OT) at school or in a private practice should be able to consult on environmental modifications and sensory accommodations. (Clin_026, p. 18)

PATIENT has a history of fine motor difficulties, and she showed handwriting difficulties during a writing sample today. She may benefit from accommodations for written communication and ongoing supportive curriculum in this area (Handwriting without Tears, Keyboarding without Tears). Accommodations could include learning to keyboard, providing answers verbally, oral presentations, or use of a scribe.

(Clin_026, p. 18)

The mismatch in this patient's IEP and clinical recommendations exposes several domains of functioning that the clinical evaluation uncovered and were not addressed by the patient's school-based evaluation and services. Importantly, this patient's IEP meeting took place during the COVID-19 pandemic.

- **Patient 36 was diagnosed at age 15 (4-Digit Diagnostic Code 1123), ND/AE**

Patient 36 was found eligible for special education services and an IEP one year prior to their evaluation at the FAS DPN clinic under the Emotional Behavioral Disability category. The patient's IEP directly acknowledges her struggle with mental health yet does not indicate specific services to address the impact of these concerns on her academic learning:

Since becoming an adolescent, PATIENT has struggled significantly with anxiety and depression. She struggles with establishing and maintaining close relationships.

PATIENT has recent incidences of self harm and suicide attempts. Her relationship with her mother is impacted by stress over homework and grades. Although PATIENT is bright with good academic skills, her difficulty self regulating emotions and attention make her unable to independently manage academic demands at this time. (IEP_036, p. 4)

The clinic agreed that "continued support through an individualized education program (IEP) is necessary" (Clin_036, p. 16) and made recommendations for a change in eligibility category, including mental health planning and specially designed instruction for executive functioning and anxiety, and including the state-required transition plan:

Based on review of records and today's visit, we recommend that PATIENT's team consider changing her eligibility category to Other Health Impaired to reflect her diagnosis within the FASD spectrum; alternatively, they may consider Multiple

Disabilities to reflect her health impairment (FASD) in addition to her Post-Traumatic Stress Disorder and Anxiety Disorder diagnoses. (Clin_036, p. 17)

... we believe that it is of paramount importance that PATIENT's school staff immediately engage in efforts designed to identify what factors promote the feeling of safety to PATIENT, and work to ensure that these factors are present so that PATIENT is able to engage in learning during her school day. (Clin_036, p. 17)

In addition to the impact of trauma-related stress and anxiety on PATIENT's learning, PATIENT does have neurodevelopmental conditions that result in deficits in executive functioning. When anxiety and traumatic stress symptoms are triggered and the brain is engaged in scanning for safety and/or in "fight-flight-freeze" mode, executive functioning skills become even more difficult to access. Therefore, PATIENT's deficits in EF are compounded by anxiety (including anxiety triggered by traumatic stress symptoms). (Clin_036, p. 17)

The team strongly recommends that PATIENT's IEP include: Specially-designed instruction (SDI) designed to help PATIENT learn to reduce the impact of anxiety and stress on academic engagement and functioning. (Clin_036, p. 17)

Consideration of related and/or supplementary services to ensure that needs are met regarding trauma- and anxiety-related intervention. PATIENT is in need of mental health provider/s who are skilled in addressing complex trauma and anxiety presentations, and

her school team should have dedicated time and resources for consultation with such provider/s due to the significant adverse impact these symptoms are imposing on her educational engagement and access. (Clin_036, p. 17)

PATIENT's IEP should include a transition plan, which is a multiyear plan aimed at preparing students for life after graduation... It helps to guide services, goals, and objectives for each of the annual IEP... Her transition plan can and should include resources for helping PATIENT explore and experience a range of vocational options so that she can find options that are a good fit. (Clin_036, p. 18)

Although the patient's IEP acknowledged the presence of significant mental health concerns, it did not include services, goals, or planning structures aligned with the clinical team's recommendations for executive functioning support, trauma-informed intervention, or transition planning. This case therefore represents an example of no match between clinical recommendations and IEP-documented services.

- **Patient 60 was diagnosed at age 9 (4-Digit Diagnostic Code 114(3)3; brain function rank of 3), FAS**

This patient was being seen for a re-evaluation at FAS DPN. The patient was diagnosed eight years prior with ND/AE (4-Digit Diagnostic Code: 1123) as a baby. Their eligibility category for special education was under Developmental Delay at the time of their evaluation at FAS DPN. Recommendations from the FAS DPN team include a change in eligibility category and continued support from the OT and SLP as identified already in their IEP:

His diagnosis today indicates that he should qualify for an IEP as a student with "Other Health Impairment. (Clin_060, p. 16)

He should continue working with his occupational therapist and speech-language pathologist as part of his IEP. (Clin_060, p. 16)

The clinical team made recommendations for the addition of specialized instruction and support for all academic subjects (previously discontinued), developing social skills, processing speed challenges, and increasing support around attention and focus:

We strongly recommend that PATIENT's educational team re-introduce specially-designed instruction in all academic areas for PATIENT so that he can progress towards age-appropriate and functional academic skills. (Clin_060, p. 17)

PATIENT would benefit from specially-designed instruction in social skills and social decision-making to improve his skills in social safety, self-advocacy, and in development of relationships. (Clin_060, p. 17)

Processing speed challenges (as observed across all domains of functioning, including motor skills, academic skills, language and social communication, and adaptive skills) must be well-understood by all of his educational team so that his need for processing speed allowances are met appropriately and learning opportunities are not missed by adults who move on before PATIENT has had sufficient time to process (his response, identify and articulate his need for support or clarification, etc.). (Clin_060, p. 17)

PATIENT is in need of accommodations for attention/focus, and written expression/reading. (Clin_060, p. 17)

Patient 60's case illustrates how a patient's diagnosis can reveal service discontinuities that are not fully captured in IEP documentation. Although the patient had longstanding involvement in special education and continued occupational therapy and speech-language pathology services, the interdisciplinary clinical evaluation at FAS DPN identified a need to reintroduce specially designed instruction across academic domains that had previously been discontinued. Clinical recommendations further emphasized processing speed, attention, and social cognition as critical factors affecting access to learning—domains that were not explicitly addressed in the patient's existing IEP. This case highlights how evolving neurodevelopmental profiles may necessitate substantive changes in service configuration, even for students with early identification and long-term special education involvement.

Across Low-/No-Match cases, misalignment most often reflected clinically identified neurodevelopmental needs as unacknowledged in IEP-documented services, rather than complete absence of special education support. Common patterns included missing related services (e.g., occupational therapy, speech-language pathology), eligibility categories that did not fully capture the student's functional profile, and goals that targeted surface-level academic performance without addressing underlying cognitive deficits. Timing of evaluations and pandemic-related constraints appeared to influence documentation quality in several cases, though misalignment persisted even when school-based evaluations were relatively recent.

Differences in Subpopulations

Several findings related to demographic variables of interest in this study warrant additional qualitative context to illustrate quantitative results. More specifically, the presence of an ADHD diagnosis applied to more than three-quarters (84%) of the patients with IEPs in this study, just over half of the patients with IEPs were female, almost 30% of patients attended school in a rural

school district, and about one-third of patients' IEPs were missing occupational therapy to support deficits identified in the clinical evaluation. The following cases were selected to provide qualitative context for patterns observed in the quantitative analyses, illustrating how demographic and contextual variables—including comorbid ADHD, sex, school district geography, and service identification—may shape the alignment between interdisciplinary clinical recommendations and IEP-documented services.

- ***ADHD Diagnosis (2 patients).*** 38 out of 45 patients with IEPs (84%) had a preexisting ADHD diagnosis at the time of their evaluation at FAS DPN. Two patients here capture some of the clinical evaluation outcomes when there is a co-occurrence of ADHD and FASD.

- **Patient 39 was diagnosed at age 14 (4-Digit Diagnostic Code: 1124), ND/AE**

This patient case provides an example of school supports capturing most of the challenges the patient is experiencing in terms of skill development and specially designed instruction. The clinical team at FAS DPN did not recommend a change in eligibility category (the patient was already under Other Health Impairment given their ADHD diagnosis) and acknowledged a missing transition plan for the patient; otherwise, no educational recommendations were made as the patient's IEP accurately reflected the patient's areas of strengths and weaknesses:

PATIENT will continue to benefit from an individualized education program (IEP) as a child with "Other Health Impairment". Her current program appears to address her primary areas of need, but we encourage the family to share results from this assessment with her school team to inform future educational planning. PATIENT may benefit from multiyear educational planning through a transition plan. In particular, PATIENT may

benefit from goals and accommodation related to social-emotional-behavioral health.

(Clin_039, p. 16)

Patient 39's case demonstrates that when ADHD is already recognized and appropriately conceptualized within an IEP eligibility framework (i.e., OHI), alignment between clinical recommendations and school-based supports may be strong. In this case, the FAS DPN clinical team largely affirmed the adequacy of existing services, identifying only the absence of a transition plan as an area for future planning. This case provides an important contrast within the ADHD subgroup, illustrating that comorbid ADHD does not inherently predict misalignment when eligibility, services, and supports accurately reflect the student's functional profile.

- **Patient 63 was diagnosed at age 11 (4-Digit Diagnostic Code of 2134), SE/AE**

Patient 63 was found eligible for special education and an IEP under the category Specific Learning Disability in reading and mathematics (with a history of developmental delay and a diagnosis of ADHD). The clinical team at FAS DPN agreed that an IEP was appropriate for this patient, and the team still provided a recommendation for an eligibility category change:

To capture her complex profile of disabilities, we would recommend that her eligibility category be changed to "Other Health Impaired" or "Multiple Disability."

(Clin_063, p. 16)

The FAS DPN determined several areas of need for this patient that were not addressed in her most recent IEP. Of note, the timing of this patient's appointment at FAS DPN and their upcoming IEP meeting were notably close; this patient was seen at FAS DPN one month before their scheduled annual IEP meeting. It's possible that some of these areas would be addressed through concerns from teachers (and the need to update their IEP goals) and caregiver concerns.

The clinical team recommended adding occupational therapy and specific goals for the OT to address:

Given her multiple adaptive behavioral skills, lack of independence with self-care, challenges with community access, and sensory processing concerns, we strongly recommend that an occupational therapist (OT) be part of her IEP team. She should have specific goals in her IEP related to social skills, self-care, safety, and community access... Given the multiple sensory processing differences reported today along with significant adaptive behavior concerns in areas such as self-care, community access and other areas, occupational therapy services are recommended. (Clin_063, pp. 16-17)

The clinical team at FAS DPN also made recommendations for mental-health and trauma-informed approaches to supporting the patient:

School staff working with PATIENT should be trained in and should use trauma-informed strategies such as those available from Compassionate Schools ...

(Clin_063, p. 17)

Finally, the clinical team recommended a social skills group to support the patient's challenges with peer relationships not addressed by her current IEP services:

A social skills group that focuses on forming and maintaining friendship would be beneficial. Social skills groups may be found at school or within the community.

(Clin_063, p. 17)

Despite a relatively recent school-based triennial evaluation, multiple clinically identified needs—including sensory processing, adaptive functioning, social skills, and mental health supports—were not adequately addressed in the patient's IEP, indicating persistent misalignment

between clinically identified needs and IEP-documented services despite relatively recent school-based evaluation.

- ***Sex Differences.*** 23 of the 45 patients with IEPs were female, which is just slightly over 50%. The case presented below represents a female teenager who was late in adolescence when she received an evaluation at FAS DPN to clarify her diagnostic and neurodevelopmental profile and needs.
 - **Patient 40 was diagnosed at age 17 (4-Digit Diagnostic Code 4132), SE/AE**

This patient is a case example in which a female’s diagnosis of FASD not only came last in adolescence but also demonstrated persistent gaps in school evaluations and services for a female student. The clinical team agreed with her need for an IEP and made a recommendation to consider changing her eligibility category from Specific Learning Disabilities (for reading, writing, and mathematics) to Other Health Impaired:

Educational support through an individualized education program (IEP) continues to be appropriate to *[sic]* for PATIENT. Her IEP team can consider whether a change in eligibility category to “Other Health Impaired” would better capture PATIENT’s pattern of disabilities. (Clin_040, p. 16)

The team recommended an out of cycle from triennial evaluation (given the patient’s age and timeline:

Results from this FASD diagnostic evaluation indicate challenges with organization/planning, executive functioning, memory, sensory-motor skills (and complex communicative discourse be considered in this evaluation. A re-evaluation may be useful to add supports for existing goals. We recommend that formal assessment of adaptive skills, sensory-motor functioning (fine motor, gross motor, handwriting), and

more complex aspects of communication (e.g., expository discourse, conversational skills, persuasive discourse, metalinguistic skills, non-literal and ambiguous language) be included in this evaluation. (Clin_040, p. 16)

The clinical team further recommended specially-designed instruction in the areas of planning and organizing tasks and assignments (executive functioning skills), as well as reading and language comprehension:

Specially-designed instruction could target skills such as planning and organizing multi-step tasks and long-range assignments. This can include using and filling out planners and calendars. Additional instruction to support self-advocacy in requesting use of existing and other needed accommodations around organizational and planning skills should be included. (Clin_040, p. 17)

Specially-designed instruction to support reading and language comprehension could target continued improvement of more complex aspects of language and complex discourse, as well as development of compensatory strategies (e.g., graphic organizers and mnemonic strategies) to support learning of information from written sources and lectures. (Clin_040, p. 17)

“Because of sensory and attentional issues, a trial of sensory accommodations may be useful ... Modifications of the classroom environment may be useful, such as a “quiet office” space to assist in focusing at school/work, noise-canceling headphones, or the use of techniques such as keyboarding. Consultation from an occupational therapist may be beneficial to identify accommodations. (Clin_040, p. 17)

Finally, Patient 40's IEP was missing a transition plan, which is required by Washington state law by the age of 16:

A transition plan should be part of PATIENT's IEP, which would include information on community living, DVR, job programs, and social opportunities. (Clin_040, p. 16)

Patient 40's case illustrates how delayed identification of FASD in female students may coincide with gaps in school-based evaluation, eligibility classification, and service planning during adolescence. Despite clear clinical identification of executive functioning, sensory-motor, language, and adaptive needs, the patient's IEP lacked corresponding specialized instruction, related services, and a legally required transition plan, reflecting substantial misalignment during a critical developmental period.

- ***School District Geography (Rural).*** 13 of the 45 patients with IEPs were in rural school districts, which makes up about 28% of the patients who were evaluated at FAS DPN. The case presented illustrates potential resource-limited constraints on a school team's ability to provide the services and accommodations as recommended by the clinical team.

- **Patient 43 was diagnosed at age 10 (4-Digit Diagnostic Code 1124), SE/AE**

This patient was evaluated at FAS DPN two months after their school-based re-evaluation and FBA. Those results indicated eligibility for special education under the category Emotional/Behavioral disability, which was a recent category change from OHI:

A review of records including reviewing his last "evaluation" concluded on xx/xx/xxxx in the ... School District. At that time, it was concluded by PATIENT's eligibility team that he qualified for special education services under the special education classification of: Other Health Impairment (OHI). This was based on a referred-to medical diagnosis consisting of: Depression, ADHD, & anxiety. (IEP_043, p. 5)

The patient's re-evaluation determined that under their eligibility for special education services, the patient receives specially designed instruction in social/emotional, behavior, social skills, and adaptive skills. The clinical team at FAS DPN concurred with the diagnosis of EBD:

Continued support from an individualized education program (IEP) as a student with emotional-behavioral disability is appropriate for PATIENT. His IEP should include appropriate accommodation for his anxiety disorder. (Clin_043, p. 18)

The clinical team provided recommendations for additional accommodations to be included in the patient's IEP to address anxiety, processing time, safety, and self-regulation, as well as sensory sensitivities:

Other accommodations to consider include:

- o Preferential seating and a safe place to retreat when PATIENT needs to self-regulate.
- o Allow testing to occur in smaller settings with reduced distraction
- o Allow extra time for processing (for example, when answering a question in class, wait longer for PATIENT to formulate an answer)
- o Identify a "trusted-adult" mentor that PATIENT can go to for help managing stress/anxiety. (Clin_043, pp. 18-19)

PATIENT has sensory sensitivities particularly to touch and loud noises which likely contribute to his anxiety and adaptive behavior difficulties. Examples of accommodations that may be helpful include modifications of the classroom environment, such as a "quiet office" space to assist in focusing at school, headphones, or fidgets. ... The occupational therapist (OT) at school or in a private practice should be able to consult on environmental modifications and sensory accommodations. (Clin_043, p. 19)

In the case highlighted here, attending a rural district did not appear to be a barrier for accurate diagnosis of disability and needs for the patient. This case suggests that although rural district placement may pose structural constraints in some contexts, geographic location alone does not preclude accurate identification of disability or alignment between clinical recommendations and IEP-documented supports.

- ***Missing Service: Occupational Therapy.*** As demonstrated by quantitative results, occupational therapy was the most commonly misaligned area of need for students with existing IEPs. The FAS DPN clinic recommended the addition of occupational therapy services to a patient's IEP for about one-third ($n = 14$) of patients and recommended changes in existing occupational therapy services for 10 patients (22%).

- **Patient 68 was diagnosed at age 9 (4-Digit Diagnostic Code 3133), SE/AE**

Patient 68 had a current IEP that provided her with specially designed instruction in the areas of behavior, reading, mathematics and communication under the eligibility category if Other Health Impaired. This patient attends a tribal elementary school on the Tulalip Reservation. Patient 68 is one of many, in addition to those already presented in other groupings, whose performance on motor and sensory assessments warranted a recommendation for specialized support and instruction by the clinical team, and yet the patient's IEP did not reflect these needs as areas of deficit:

Given today's results and observations of challenges with fine and gross motor skills and sensory processing, she would benefit from occupational therapy support at school. Handwriting needs to be evaluated carefully in the context of her functional performance. (Clin_068, p. 19)

Consider accommodations for handwriting difficulties at school. Possible accommodations include the Keyboarding without Tears Curriculum, providing answers verbally, extra time on tests, or use of a scribe. (Clin_068, p. 19)

Sensory accommodations are recommended. Examples are a “wobble pad,” weighted lap pillow, and/or headphones to be used during the school day or in homework sessions. Modifications of the classroom environment may be useful, such as a “quiet office” space to assist in focusing at school. Recess is an important chance for movement, which should never be eliminated as a classroom discipline strategy. Scheduled “down time” in a quieter, calmer space can help. The occupational therapist (OT) at school or in a private practice should be able to consult on environmental modifications and sensory accommodations. (Clin_068, p. 19)

Patient 68’s case exemplifies a significant occupational therapy service gap, in which fine motor and sensory processing deficits were clearly identified through interdisciplinary clinical assessment but were not reflected in IEP-documented services or accommodations. Despite evidence from direct testing that the patient has a need for occupational therapy consultation, handwriting supports, and sensory accommodations, the patient’s IEP did not acknowledge these domains as areas of need, underscoring occupational therapy as a recurrent point of misalignment across numerous cases in this study.

The Differences in Subpopulations cases extend findings from RQ6 by illustrating how alignment between interdisciplinary clinical recommendations and IEP-documented services may vary as a function of diagnostic complexity, comorbid ADHD, sex, school district context, and service availability. In particular, occupational therapy emerged as a consistent area of

service gap, while ADHD diagnosis and rural school placement were associated with both high and low alignment depending on contextual factors.

Chapter 5: Discussion

In this final chapter, results are summarized and synthesized. Highlighting both key findings that address the research questions that drove this study, as well as unexpected findings that emerged, implications and recommendations for educational planning and clinical practice for school-aged children diagnosed with FASDs are presented. The chapter closes with a discussion of study limitations, directions for future research, and concluding remarks.

Summary of Findings

The present study set out to explore how well a patient's IEP aligned with the FAS DPN clinical report recommendations after receiving a diagnosis of FASD. Quantitative methods were used to examine the prevalence of preexisting IEPs, demographic and diagnostic predictors of IEP services and supports, special education eligibility categories, and the extent to which there was match or mismatch between IEPs and the recommendations for educational planning from the interdisciplinary clinical team. Qualitative methods were used to further explore quantitative results by comparing the language and content of clinical reports and IEPs, with a focus on how students' neurodevelopmental and social-emotional needs were described, emphasized, or omitted across documents.

Summary and Interpretation of Quantitative Results

RQ1 examined the prevalence of preexisting IEPs among children evaluated for FASD. Just over half of the sample (51%) had an IEP at the time of evaluation, supporting the hypothesis that more than 50% of patients would already be receiving special education services. Rates varied by diagnostic category: patients with FAS and SE/AE were more likely to have preexisting IEPs, whereas approximately one-third of patients with ND/AE had an existing IEP.

Although just over half of the sample had preexisting IEPs, nearly half did not, despite being referred for comprehensive interdisciplinary evaluation due to significant concerns. This finding highlights the ongoing under-identification of FASD-related neurodevelopmental needs within school systems (Lees et al., 2022; Petrenko et al., 2014). FASD remains substantially underdiagnosed in educational contexts, particularly among students without overt physical features (May et al., 2018). The markedly lower rate of IEP identification among students with ND/AE may reflect the likelihood that their difficulties are attributed to behavioral, environmental, or motivational factors rather than neurodevelopmental impairment (Astley, 2013). These findings suggest that diagnostic visibility and severity may influence access to school-based services prior to formal FASD identification. Students with more global impairment (e.g., FAS, SE/AE) may initiate evaluation processes earlier, whereas students with ND/AE may present with subtler profiles that are conceptualized within more common educational categories (e.g., SLD), delaying or preventing IEP development.

RQ2 investigated whether sociodemographic characteristics were associated with the likelihood of having a preexisting IEP. The hypothesis that non-White students, females, students in foster care, and homeschooled students would be less likely to have IEPs was partially supported. Non-White students, females, and homeschooled students had lower rates of IEP identification compared to White students, males, and non-homeschooled peers. In contrast, children in foster care were more likely to have IEPs than those not in foster care.

Observed differences across race/ethnicity and sex, align with longstanding patterns of disproportionality and gender bias in special education identification (says who?). Research consistently documents both overrepresentation of non-White students in certain disability categories and under-identification in others, depending on disability type and contextual factors

(Elder et al., 2021; Sullivan & Bal, 2013; Sullivan & Osher, 2019). Lower IEP rates among females are also consistent with existing literature indicating that girls with neurodevelopmental disorders are frequently under-identified due to subtler behavioral manifestations and compensatory social strategies (Arms, Bickett & Graf, 2008; Dean, Harwood & Kasari, 2017; Hinshaw et al., 2022; Rucklidge, 2010). Interestingly, children in foster care were more likely to have IEPs than their peers, contrary to the hypothesis (RQ3). This pattern may reflect increased system oversight and multidisciplinary involvement among children in foster placements, which can elevate rates of referral and evaluation (Gee, 2020; Palmieri & La Salle, 2017). That being said, higher rates of IEP identification do not necessarily equate to adequacy or appropriateness of services, underscoring the importance of examining alignment, not simply presence, of special education support.

RQ3 focused on special education eligibility categories among patients with preexisting IEPs. As hypothesized, OHI was the most common eligibility category (64%), followed by SLD and EBD. Developmental/Intellectual Disability (DD/ID) also appeared at a rate comparable to EBD. Among patients with ADHD and IEPs, OHI was especially prominent.

The predominance of OHI eligibility, particularly among students with ADHD, indicates that school teams may rely on established diagnostic frameworks to conceptualize neurodevelopmental impairment. ADHD is explicitly referenced within OHI eligibility guidance under IDEA (34 C.F.R. § 300.8), and school psychologists receive extensive training in assessment and intervention for ADHD-related difficulties (DuPaul & Stoner, 2014). As a result, ADHD may function as a proxy framework through which broader FASD-related executive functioning and self-regulation deficits are interpreted. Although this may facilitate access to services targeting attention and executive functioning, it may also obscure the broader

neurodevelopmental profile associated with PAE. The comparable rate of ID eligibility further underscores that some students in this population present with global impairment requiring broader supports than typically conceptualized under ADHD or SLD frameworks.

RQ4 examined the extent to which IEP eligibility categories aligned with the clinic's recommended eligibility. Overall, 78% of students with IEPs had eligibility categories that matched clinic recommendations and 22% were recommended for a change. Rates of disagreement did not differ substantially across diagnostic categories; however, when CNS rank was considered, nearly all cases of disagreement occurred among patients with CNS Rank 3.

Overall agreement between clinic recommendations and school eligibility categories was high (78%), and disagreement was concentrated among students with the most severe CNS dysfunction. This finding suggests that schools may be responding more directly to observable functional impairment than to categorical diagnostic labels (DuPaul et al., 2014; Frey, 2019; MacCuspie, 2016). CNS severity—which maps more closely onto functional impairment—is more educationally salient than an FASD diagnosis. The hypothesis (RQ4) assumed that diagnostic category severity would drive disagreement; however, findings indicate that functional neurodevelopmental impairment, rather than categorical label, better predicts alignment. This distinction highlights the importance of translating clinical descriptions of CNS impairment into educationally operationalized language.

RQ5 assessed whether patients with ND/AE were more likely than patients with FAS or SE/AE to have IEPs that did not match their clinically identified needs. A Fisher's Exact Test indicated a significant association between diagnostic group and IEP match status, but in the opposite direction of the hypothesis. Patients with ND/AE were more likely to have IEPs that

matched their identified needs, whereas patients with FAS and SE/AE were more likely to demonstrate partial or high mismatch across service domain.

The finding that students with ND/AE were more likely to have IEPs that matched clinically identified needs, contrary to the hypothesis (RQ5), may reflect structural alignment between ND/AE symptom profiles and existing school-based service frameworks. ND/AE is frequently characterized by executive functioning deficits, attentional regulation difficulties, and academic deficits that overlap substantially with ADHD and specific learning disability criteria (DuPaul & Stoner, 2014; Evans et al., 2014). These domains correspond directly with well-established eligibility categories and intervention models in school systems. In contrast, students with FAS or SE/AE often demonstrate more global and multi-domain neurodevelopmental impairment, including adaptive functioning challenges, sensory processing vulnerabilities, and complex emotional and behavioral regulation needs (Astley, 2013). Such complexity may not map neatly onto discrete service categories within IEP documentation, increasing the likelihood of partial or multi-domain mismatch. Rather than reflecting lesser need, higher match rates among ND/AE students may reflect greater congruence between their profiles and the categorical structures through which school services are delivered.

Table 12 synthesizes key findings from the quantitative and qualitative analyses into practice-oriented implications for school psychology. Across findings, patterns of match and mismatch between clinical recommendations and IEP documentation were more strongly associated with functional CNS impairment than with categorical FASD diagnoses, underscoring the importance of emphasizing executive functioning, adaptive behavior, and self-regulation in school-based evaluations and eligibility determinations. High agreement observed for students with FAS suggests that clearer, more widely recognized profiles may reduce ambiguity across

systems and can serve as exemplars for interdisciplinary collaboration and professional training. In contrast, higher alignment for students with ND/AE highlights the need for school psychologists to critically examine whether IEP “match” reflects true adequacy of services or reliance on familiar service models. Partial or multi-domain mismatch among students with FAS and SE/AE illustrates how some neurodevelopmental needs may exceed discrete service structures, reinforcing the need for integrated, cross-disciplinary IEP planning. Collectively, these findings emphasize the central role of school psychologists as translators between clinical neurodevelopmental findings and educational planning, with responsibility for ensuring that complex clinical information is meaningfully operationalized within school systems.

Summary and Interpretation of Qualitative Results

RQ6 asked how clinical recommendations documented in interdisciplinary diagnostic reports aligned with educational services and supports documented in students’ IEPs and what document-level patterns of match or mismatch could be identified. Across *High-Match* cases, alignment was characterized by consistent agreement on special education eligibility categories, identification of functional domains of need, and continuity in recommended services and accommodations. In several cases, alignment appeared to be supported by recent school-based evaluations or well-established IEPs that already reflected the student’s neurodevelopmental profile. Importantly, strong alignment was observed even when diagnostic terminology differed across documents, suggesting that functional need—rather than diagnostic label alone—plays a critical role in effective educational planning. These patterns provide important context for the quantitative findings reported in hypothesis 5.

Integration of Quantitative and Qualitative Findings

Collectively, these findings across the three groups (High Match, Low-/No-Match, and Differences in Subpopulations) provide explanatory depth to the quantitative results, highlighting how systemic, demographic, and procedural factors interact to shape educational service delivery for students with FASDs. Quantitative analyses showed that students with FAS and SE/AE were more likely than those with ND/AE to have IEPs that did not fully match their clinical needs, and that occupational therapy and transition planning were frequent areas of mismatch. Qualitative cases concretely illustrated these patterns: many FAS and SE/AE students had documented fine motor, sensory, or adaptive skill deficits without corresponding OT services or accommodations, and several adolescents lacked transition plans despite clear clinical recommendations.

The document review further clarified that ADHD and OHI classifications can function as both facilitators and missed opportunities. On one hand, many students with ADHD and OHI had IEPs that aligned well with clinical reports; on the other hand, Tables 10 and 11 as well as the highlighted qualitative cases show that a sizable subset of students with ADHD, with or without IEPs, still required additional evaluation, eligibility changes, or expanded services.

Finally, the high proportion of patients without IEPs for whom the clinic recommended psychoeducational evaluations, IEPs, or 504 Plans (Table 10) aligns with qualitative evidence that substantial needs may be under-identified in school settings, particularly for students whose challenges are attributed to behavior or academic underachievement rather than neurodevelopmental impairment associated with prenatal alcohol exposure. Together, the quantitative and qualitative inquiries suggest that although some school teams effectively translate clinical information into educational supports, many students with FASDs experience partial or substantial gaps between clinical recommendations and what is reflected in their IEP and special education programming.

Additional analyses extended the quantitative findings beyond the primary research questions. Among patients without preexisting IEPs (Table 10), the overwhelming majority were recommended by the clinic for further school-based evaluation and/or formal services. Nearly four out of five patients without IEPs were recommended for a comprehensive psychoeducational evaluation or IEP, and about 40% received recommendations for a 504 Plan. Only a small minority (7%) were recommended for “close monitoring” without additional services. These patterns suggest substantial unmet educational needs among youth with FASD who are not already receiving special education.

Finally, across the full sample, ADHD was highly prevalent: 70% of patients had an ADHD diagnosis (Table 11a) and 65% of those patients with IEP and ADHD diagnosis received service eligibility under the Other Health Impaired category (Table 11b). Patients with an ADHD diagnosis but no preexisting IEP ($n = 20$, 83%) were recommended for an IEP (Table 11c). This indicates that ADHD frequently co-occurs with FASD and may act as an important—though not always sufficient—marker for identifying students in need of formal supports.

Implications

Because findings of this study suggest that clinically identified needs for children with FASDs are often only partially reflected in IEP documentation—and are especially likely to be underrepresented for students with FAS and SE/AE—both school systems and clinical teams have opportunities to strengthen communication, alignment, and shared decision-making. Existing literature has demonstrated the importance of integrating clinical insights into IEPs to enhance the accuracy and responsiveness of educational planning for students with FASDs and other complex needs, yet there may be significant gaps in alignment between the additional services, supports and accommodations, and interventions the clinical team recommends and

what is already included in a child's IEP (Boys et al., 2016; Etscheidt & Curran, 2010; Flannigan et al., 2022; Kurth et al. 2025). Under IDEA, schools are required to provide appropriate supports and services based on a child's unique needs (IDEA, 2004). Findings from this research inform the need to improve and foster collaboration between clinic diagnostic teams and school-based service providers. Results from this study additionally support the widespread need for professional development for educators and school psychologists to enhance understanding of FASDs and improve IEP quality (Kautz-Turnbull et al., 2024; Millar et al., 2017).

K-12 School Settings

Results indicate that OHI is an appropriate and frequently used eligibility category for students with FASDs, particularly those with ADHD, yet disagreement between clinic and school eligibility was concentrated among students with more severe CNS impairment. School psychologists and multidisciplinary teams will benefit from additional training in FASD-specific neurocognitive profiles and in using clinical documentation (e.g., 4-Digit Diagnostic Code, CNS rank) to inform eligibility decisions, especially when considering OHI versus EBD, SLD, or Multiple Disabilities, for example. Quantitative findings and qualitative cases revealed recurrent gaps in occupational therapy and, to a lesser extent, speech-language services, even when fine motor, sensory processing, and communication deficits were clearly documented clinically. IEP teams should systematically review clinical reports for motor, sensory, and language recommendations and consider OT/SLP consultation, direct services, or accommodations when such needs are identified. For adolescents, transition planning should be prioritized and initiated within required timelines, with explicit attention to FASD-related executive functioning, adaptive skills, and mental health needs.

Table 10 showed that most students without IEPs were recommended for a formal evaluation, an IEP, and/or a 504 Plan, yet a small subset were designated for “close monitoring” only. Schools may consider structured follow-up procedures—such as scheduled review of clinical reports, progress monitoring, or problem-solving meetings with families—to ensure that recommendations for evaluation and accommodations are not lost over time. An additional school-based implication of these findings addresses the lower likelihood of IEP identification for specific groups of students, namely for non-White students, females, and homeschooled students, specifically in terms of potential inequities in referral, evaluation, or eligibility processes. School districts may need to examine their child-find practices, referral pathways, and communication strategies with families to ensure that students from historically underserved groups have equitable access to screening and evaluation when FASD or other neurodevelopmental concerns are present.

Access to special education services for students with FASDs may be shaped not only by neurodevelopmental need, but also by systemic factors related to referral pathways, caregiver advocacy, and school visibility. Lower rates of IEP identification among non-White students, females, and homeschooled students raise concerns about potential under-identification of FASD-related needs in populations whose difficulties are less likely to be externalized, observed in traditional school settings, or attributed to neurodevelopmental disability. In contrast, higher rates of IEP identification among students in foster care may reflect increased system surveillance and mandated service involvement rather than more severe need alone. From a school psychology lens, these findings raise awareness and further questions about potential referral bias, gendered presentations of executive functioning challenges and externalizing

behaviors, the visibility versus “invisibility” of need, and an overall curiosity about the equity in MTSS screening and child-find procedures in school districts across the state of Washington.

Clinical Settings

The findings from this study underscore the importance of clinical teams framing recommendations in school-relevant language that directly maps onto IEP components (e.g., eligibility categories, service domains, accommodations, and transition plans). The inclusion of clear, concise summary sections that translate neuropsychological findings into concrete educational recommendations may increase the likelihood that school teams can implement them. Because this study did not track whether recommendations were implemented, it is unknown how often clinical guidance translates into IEP changes. Clinicians might consider establishing systematic procedures for sharing findings with school personnel (with caregiver consent), participating in IEP meetings when possible, or offering brief consultation calls to help teams interpret recommendations. Finally, with 70% of the sample having ADHD and many presenting with significant anxiety, trauma histories, or other mental health concerns, clinical teams are well positioned to highlight how these conditions interact with FASD-related executive functioning and learning. Clear recommendations for trauma-informed practices, executive functioning supports, and coordination with school-based mental health providers may help bridge gaps observed in several *Low-/No-Match* cases.

Timing of Clinical Evaluation Relative to School-Based Evaluations

An important contextual factor that may have influenced patterns of match and mismatch observed in this study is the timing of the interdisciplinary clinical evaluation relative to school-based evaluation cycles and IEP development. Although this study did not systematically analyze time elapsed between clinical diagnosis and subsequent IEP review or reevaluation, document

review suggested meaningful variability in how recently students had undergone school-based evaluation at the time of their FASD diagnostic assessment. For some patients, the clinical evaluation appeared to precede a scheduled triennial reevaluation by several months to one or two years, and in some cases preceded an upcoming IEP review by eight to ten months. In these cases, it is possible that the clinic evaluation effectively “beat the school to it,” providing new or expanded information that could be reasonably incorporated into subsequent school-based assessments. For these students, apparent alignment between clinical recommendations and IEP documentation may reflect a natural sequencing in which schools later evaluated additional areas of need (e.g., executive functioning, adaptive skills, motor or sensory processing) as part of their regular reevaluation processes. From a school psychology perspective, this pattern is consistent with best practice, in which external clinical information informs future assessment planning and eligibility decisions.

In contrast, for students who had undergone a recent school-based evaluation (with recent being determined as within the prior six months), the presence of substantial gaps between clinically identified needs and IEP-documented services raises different interpretive questions. In these cases, the proximity of the school-based evaluation to the clinical assessment suggests that schools had a recent opportunity to assess functional domains relevant to educational planning. When significant needs—particularly in areas such as occupational therapy, sensory processing, or adaptive functioning—were clearly documented in the clinical report but absent from the IEP, this discrepancy may reflect limitations in assessment scope (especially if a school-based occupational therapist was not a part of the evaluation or IEP team), differences in conceptual frameworks, or challenges translating neurodevelopmental findings into educationally operationalized services rather than simple timing effects alone.

These timing-related considerations highlight the dynamic nature of educational planning for students with FASDs. School-based evaluations and clinical evaluations alike represent snapshots of functioning at a particular moment, yet students' neurodevelopmental needs evolve over time, and no single evaluation can be expected to fully capture emerging challenges. For school psychologists, these findings underscore the importance of viewing clinical evaluations not as static documents, but as data points that should inform ongoing assessment planning, progress monitoring, and reevaluation decisions within MTSS and special education frameworks. Proactive follow-up, targeted supplemental assessment, and interdisciplinary consultation may be particularly critical when new clinical information emerges shortly after a school-based evaluation has been completed, and thus timing cannot be ignored as a factor when examining why a school may have “missed” specific needs for a student.

Emphasizing Services Over Labels

A salient finding of the present study was the high prevalence of ADHD diagnoses within the sample, with approximately 70% of patients meeting criteria for ADHD. This finding is consistent with existing literature documenting substantial symptom overlap between ADHD and FASD, particularly in domains of executive functioning, attention regulation, impulse control, and emotional and behavioral self-regulation (Khoury & Milligan, 2019; Kingdon, Cardoso & McGrath, 2016; Waite & Burd, 2023). In school settings, an ADHD diagnosis—often operationalized through the OHI eligibility category—may therefore function as a reasonable “entry point” to services for students whose underlying neurodevelopmental vulnerabilities are related to prenatal alcohol exposure, especially without a formal diagnosis of an FASD. In this sense, ADHD-based identification may facilitate access to supports that address core areas of need and is arguably preferable to the absence of formal recognition or services altogether. At the

same time, reliance on ADHD as a primary disability for IEPs may only partially capture the complexity of students' needs. Even though ADHD-oriented services may effectively target attention, executive functioning, and behavioral regulation, they are less likely to systematically address additional domains frequently associated with FASDs, including adaptive functioning, sensory processing, motor coordination, social cognition, and broader learning weaknesses.

Findings from the present study suggest that although students with ADHD—and particularly those classified under OHI—were more likely to have IEPs that appeared to match better with clinical recommendations, this apparent alignment may reflect familiarity with ADHD-based service models rather than comprehensive responsiveness to the full neurodevelopmental profile of a student with prenatal alcohol exposure. Thus, ADHD identification may support functional access to services while simultaneously overshadowing the need for more integrated, cross-domain intervention planning.

From a school psychology perspective, these findings reinforce the principle that educational services should be determined by documented functional need rather than disability label alone, as emphasized under IDEA. Eligibility categories are intended to provide access to services, not to constrain the scope of intervention. The high prevalence of ADHD in this sample highlights both an opportunity and a risk: ADHD identification may reduce barriers to support for students with FASDs, yet it may also narrow the lens through which their needs are conceptualized. School psychologists play a critical role in ensuring that IEP teams move beyond diagnostic shorthand to consider the full range of neurodevelopmental impacts documented in clinical evaluations, regardless of whether the formal eligibility category is OHI, SLD, or another classification (NASP, 2020). In this way, ADHD-based identification can serve as a starting point—but not an endpoint—for educational planning, underscoring the importance of

comprehensive assessment, interdisciplinary collaboration, and ongoing review of service adequacy as students' needs evolve over time in their academic careers.

What's the Deal with Occupational Therapy?

A consistent pattern across both quantitative and qualitative findings was the underrepresentation of occupational therapy services in students' IEPs, even when fine motor, sensory processing, and functional needs were clearly documented in clinical evaluations. This recurrent gap suggests that occupational therapy may represent a critical point of misalignment between how neurodevelopmental needs are conceptualized in clinical versus educational systems. Despite the interdisciplinary clinical team frequently identifying these domains of need as central to students' daily learning and self-regulation, they were not consistently represented or addressed in school-based services or accommodations as written in the patient's IEP. For students with FASDs, this omission is particularly consequential. These are not peripheral skills; these skills directly support attention, task persistence, handwriting, classroom engagement, emotional regulation, and adaptive behavior. When these foundational domains of functioning are insufficiently addressed, academic and behavioral interventions alone may have limited effectiveness for the student and lead to further negative academic and behavioral consequences. Thus, the absence of occupational therapy services in IEPs—even in cases with clear clinical indication—may reflect not a lack of need, but a systemic tendency to prioritize academic targets over underlying regulatory and functional capacities that enable learning to occur in the first place.

One way to interpret the recurrent OT mismatch observed in this study is that school-based teams may implicitly conceptualize occupational therapy as ancillary or supplemental rather than integral to educational access. Academic skills such as reading and mathematics, and

behavioral concerns such as compliance or attention, are often prioritized in eligibility and service decisions, whereas sensory-motor and functional participation needs may be viewed as secondary unless they present as overt physical disabilities. However, for students with FASDs—whose learning is frequently mediated by difficulties in sensory processing, motor coordination, and self-regulation—occupational therapy targets the very mechanisms through which academic instruction and behavioral supports are accessed. From this perspective, OT-related needs may be especially vulnerable to under-identification when eligibility categories such as OHI or SLD are used. Although these categories may appropriately capture aspects of attention and behavior, they do not inherently prompt systematic consideration of motor and sensory domains. Thus, the findings of this study suggest that without explicit attention to these areas, IEPs may appear aligned on paper yet fail to address key functional barriers to learning—contributing to the partial or multi-domain mismatch observed for many students with FAS and SE/AE.

Furthermore, these findings highlight a critical role for school psychologists in ensuring that occupational therapy considerations are meaningfully integrated into educational planning for students with FASDs. As professionals trained to interpret neurodevelopmental data across cognitive, behavioral, and adaptive domains, school psychologists are uniquely positioned to recognize when motor and sensory needs are functionally impacting educational performance—even when those needs do not align “neatly” with traditional academic metrics. This includes advocating for targeted OT assessment, consultation, or services when clinical documentation indicates sensory or motor vulnerabilities and helping multidisciplinary teams understand how these domains interact with attention, behavior, and learning. In doing so, school psychologists can help shift IEP planning from a focus on surface-level academic or behavioral outcomes to a

more comprehensive understanding of the foundational capacities that support student engagement and success.

Significance of Patients Without IEPs

A particularly striking finding from the present study was the size of the subgroup of patients who did not have a preexisting IEP at the time of their FASD diagnostic evaluation, despite the majority of these students being recommended for formal school-based evaluation, special education services, and/or 504 Plans. Nearly four out of five students (79%) without IEPs were identified by the interdisciplinary clinical team as requiring further evaluation or structured educational supports, suggesting substantial unmet need within this group. This pattern indicates that lack of an IEP at the time of clinical evaluation does not necessarily reflect absence of educational impact, but may instead reflect delayed identification, limited access to services, or thresholds for concern that are misaligned with the neurodevelopmental presentation of FASDs. From a developmental perspective, this finding is especially concerning given the vulnerability of students with FASDs to cumulative skill gaps over time. When neurodevelopmental challenges related to attention, executive functioning, adaptive behavior, and emotional regulation are not identified early, academic and behavioral demands may gradually exceed students' capacities, resulting in escalating difficulties that only later trigger formal evaluations.

The presence of significant clinically identified needs among students without IEPs suggests that many may not receive targeted support until difficulties have become unmanageable, rather than during earlier periods when intervention may be most effective. Viewed through an MTSS framework, the large proportion of students without IEPs who nonetheless demonstrated clear clinical need highlights potential gaps in Tier 1 and Tier 2 identification and intervention processes. Students with FASDs may not consistently present with

the kinds of academic failure or disruptive behavior that prompt immediate referral, particularly in early elementary grades. Instead, their difficulties may emerge as subtle inefficiencies in learning, regulation, or task persistence that are more easily attributed to motivation, attention, or environmental factors. Without systematic screening or structured problem-solving processes that explicitly consider neurodevelopmental vulnerability, these students may cycle through general education supports without receiving sufficiently targeted intervention.

The findings of this study suggest that earlier integration of clinical information into MTSS decision-making could help reduce these delays. Clinical evaluations identifying prenatal alcohol exposure, CNS impairment, or related executive functioning vulnerabilities could inform more proactive Tier 2 or Tier 3 supports, even in the absence of an existing IEP. In this way, MTSS offers a structured framework for responding to identified needs and delivering school-related services without requiring immediate categorical eligibility, potentially reducing the number of students whose needs remain unaddressed until later, more intensive intervention is required. The group of patients without IEPs in this study underscores the school psychologist's role in early identification, consultation, and advocacy. School psychologists are often the professionals responsible for interpreting early patterns of concern, guiding MTSS problem-solving teams, and determining when comprehensive evaluation is warranted. For students with FASDs, whose profiles may include uneven skill development and delayed manifestation of academic impact, these decisions are particularly complex. The fact that only a small minority of students without IEPs were recommended for "close monitoring" alone suggests that clinical teams identified meaningful functional concerns even when school-based systems had not yet formalized services. This discrepancy highlights the importance of school psychologists maintaining a broad conceptualization of educational impact—one that includes not only current

academic performance, but also functional capacities that support learning over time. Proactive consultation, targeted assessment, and ongoing monitoring may be especially critical for students with FASDs to prevent the accumulation of unmet needs and secondary difficulties.

Collectively, these findings challenge the assumption that students without IEPs are functioning adequately within general education settings. For students with FASDs, the absence of formal services may reflect systems-level barriers rather than resilience or lack of impairment. By highlighting the substantial proportion of students without IEPs who nonetheless required additional evaluation or supports, this study reinforces the importance of early, developmentally informed identification practices and the use of tiered supports to address emerging needs before they escalate. For school psychologists, this finding emphasizes the ethical and professional responsibility to look beyond categorical status and respond to functional need wherever it appears within the educational system.

Study Limitations

This study offers a unique contribution to the literature on the alignment between interdisciplinary FASD diagnostic evaluations and school-based IEP documentation. As with many studies, however, there are limitations that must be considered when interpreting the findings. Among these limitations include the context of the COVID-19 pandemic, lack of patient follow-up after a completed evaluation at the FAS DPN, generalizability of the findings, and the study design.

COVID-19. The COVID-19 pandemic context likely constrained the scope of some school-based evaluations and goal development, particularly for IEPs written or amended between 2020 and the early years of the pandemic. Remote learning, service disruptions, and

shifting instructional models may have influenced both the quality of documentation and the availability of services, especially related to OT, SLP, and social-emotional supports.

Patient Follow-Up. Because this study did not include follow-up with caregivers, school teams, or patients themselves, results are limited to information written in clinical reports and educational documents. There were no additional data sources (e.g., interviews, observations, IEP meetings) to determine whether recommended changes were considered or implemented at subsequent IEP meetings. Thus, this study cannot speak to the actual impact of clinical evaluations on later educational decision-making or student outcomes.

Generalizability. The sample is clinic-based and does not necessarily represent all school-aged individuals with FASD in the general population. The sample includes only residents of Washington State, thus is primarily reflective of Washington school districts and IEP processes. Thus, the study relied on a relatively small and regionally constrained sample which may not capture the full variability in demographic, socioeconomic, or educational contexts experienced by children with FASD nationwide. Differences in state-level eligibility criteria, funding models, and access to specialized services may limit the generalizability of these results to other regions.

Study Design. The secondary review and analysis design of this study imposes inherent constraints. Analyses were limited to information documented in existing clinical reports and IEPs, which likely varied in depth and consistency and likely omitted contextual nuances relevant to decision-making from the school-based IEP team. Furthermore, because this study focused exclusively on the degree of alignment between clinical recommendations and IEP provisions, it did not evaluate educational or functional outcomes for the patients once they received their evaluation and diagnosis from FAS DPN. Thus, conclusions cannot be drawn

about whether the recommendations from the clinical evaluation resulted in improved IEP documentation or change in special education support and services in school.

Though these limitations should be considered, they highlight opportunities for future studies to deepen and expand this area of inquiry. In particular, the gaps identified between clinical recommendations and IEP documentation suggest that more comprehensive, multi-informant research designs are warranted to understand both the processes and outcomes of school–clinic collaboration for students with FASD. Future work can build on these findings to test strategies for improving alignment and to evaluate their impact on student trajectories over time.

Recommendations for Future Longitudinal Research

An important direction for future research is the use of longitudinal designs to examine how alignment between clinical recommendations and school-based IEPs evolves over time following an FASD diagnostic evaluation. The present study relied on a secondary review of existing clinical reports and IEP documents, which necessarily captured alignment at a single point in time. As a result, it was not possible to determine whether IEPs were subsequently revised, services were added, or eligibility categories were reconsidered following the clinical evaluation. In some cases, an apparent mismatch at the time of document review may reflect a timing issue rather than a persistent failure of alignment, particularly if IEP teams had not yet met to incorporate new clinical information—and whether a family decided to share the clinical report with the team at all. Future research that explicitly examines the temporal relationship between clinical diagnosis, school-based evaluation cycles, and subsequent IEP revision would help clarify how timing influences alignment and service delivery for students with FASDs.

Longitudinal research could address the critical question of “what happened next” by following students across multiple IEP cycles after diagnosis. Such designs would allow researchers to examine whether and how clinical recommendations are translated into educational programming over time, including changes in eligibility categories, services, accommodations, and transition planning. Cognitive, adaptive, and self-regulatory demands increase substantially as students progress through school, and educational needs may shift accordingly. A single clinical evaluation cannot be expected to fully capture or predict a child’s educational needs nine months, one year, or several years later.

From a school psychology perspective, longitudinal research of this topic would also provide insight into how timing and developmental vulnerability interact with school-based decision-making. Early childhood and early elementary years represent periods of heightened neurodevelopmental plasticity in multiple neural systems, during which timely identification and intervention may mitigate later academic and functional difficulties and improve long-term cognitive and functional outcomes (Nelson, Sullivan & Engelstad, 2024). Delays in translating clinical recommendations into educational supports may contribute to cumulative skill gaps, increased behavioral challenges, or secondary mental health concerns over time (Kim, 2021; Sperandini et al., 2026). Future studies could examine whether earlier alignment between clinical recommendations and IEP services is associated with more favorable educational trajectories for students with FASDs.

Longitudinal research is also needed to clarify the interpretation of “IEP match” observed in the present study. As discussed, IEP alignment does not necessarily indicate adequacy of services. Students with ND/AE demonstrated higher rates of apparent alignment, which may reflect the fact that their profiles map more closely onto familiar school-based eligibility

categories and service models. Longitudinal designs could evaluate whether such alignment results in improved academic, behavioral, or adaptive outcomes, or whether it reflects comfort with familiar profiles rather than comprehensive responsiveness to the complexity of prenatal alcohol exposure. In contrast, students with FAS and SE/AE—who showed higher rates of partial or multi-domain mismatch—may require more developmentally responsive adjustments to their educational programming over time.

Future longitudinal studies should incorporate multiple data sources, including repeated IEP reviews, caregiver and educator interviews, and school psychologist reports, to better capture the processes by which clinical information is integrated (or not) into educational planning. Such work would provide critical guidance for school psychologists, who play a central role in monitoring student progress, triennial reevaluations for eligibility and services, and ensuring that educational plans remain responsive as students with FASDs develop and face increasing academic and functional demands.

Early Intervention and MTSS Frameworks

Future longitudinal research examining educational trajectories for students with FASDs would also benefit from explicit integration with MTSS and early intervention frameworks. MTSS emphasizes early identification, tiered intervention, ongoing progress monitoring, and data-based decision-making—principles that align closely with the needs of children with FASDs, whose neurodevelopmental profiles often involve emerging and evolving challenges across academic, behavioral, and adaptive domains. A longitudinal MTSS-informed design could examine how students with FASDs move across tiers of support following clinical diagnosis and whether receiving an interdisciplinary evaluation served as a catalyst for more targeted intervention. For example, future studies could investigate whether students who receive timely,

functionally grounded supports at Tier 2 or Tier 3 following diagnosis demonstrate improved outcomes relative to students whose needs are addressed only after significant academic or behavioral failure has occurred. Such work would clarify whether earlier alignment between clinical recommendations and school-based supports functions as a protective factor, particularly during periods of heightened developmental vulnerability.

School psychologists are often responsible for coordinating MTSS implementation, interpreting progress monitoring data, and determining when a student's response to intervention indicates the need for more intensive or individualized supports. Longitudinal research could illuminate how clinical information—such as CNS rank, executive functioning vulnerabilities, or adaptive skill deficits—is incorporated into MTSS decision-making processes and whether such integration improves the accuracy and timeliness of evaluation for special education eligibility. Importantly, MTSS frameworks also provide a mechanism for addressing the interpretive caution raised in the present study: that IEP match does not necessarily equate to adequacy. Longitudinal designs could assess not only whether IEPs align with clinical recommendations, but whether students demonstrate meaningful progress in response to implemented supports. In this way, MTSS-based outcome data could help distinguish between superficial alignment (i.e., services that appear appropriate on paper) and effective intervention (i.e., supports that result in measurable gains in functioning). In other words, longitudinal designs would incorporate progress monitoring which is an essential features of MTSS.

Finally, integrating longitudinal research with MTSS would allow investigators to examine how educational planning for students with FASDs evolves across developmental transitions, such as entry into elementary school, the shift to middle school, and the onset of adolescence. These transition points often coincide with increased academic demands and

executive functioning expectations and may represent critical windows for proactive intervention. Understanding how clinical recommendations are revisited, revised, or overlooked across these stages would provide actionable guidance for school psychologists seeking to implement developmentally responsive supports for students with FASDs.

Conclusion

The purpose of this study was to examine how well school-based IEPs reflect the neurodevelopmental and functional needs identified in interdisciplinary FASD diagnostic evaluations and to identify factors associated with match or mismatch between clinical recommendations and educational planning. Grounded in a framework that examined quantitative and qualitative data, this study sought to better understand **how** and **why** alignment varies across students with FASDs, and what these patterns suggest for school-based decision-making. Findings from this study indicate that alignment between clinical recommendations and IEP documentation is common but far from universal. While many students—particularly those with ND/AE and those with well-established educational plans—had IEPs that reflected clinically identified needs, a substantial proportion of students experienced partial or significant gaps between documented neurodevelopmental needs and school-based services. These gaps were most pronounced for students with FAS and SE/AE and for those with more severe CNS impairment, whose needs frequently spanned multiple functional domains that were not fully captured within existing eligibility categories or school special education service structures.

Consistent with the framing introduced at the outset of this dissertation, the findings highlight that alignment between clinical and educational systems is shaped less by diagnostic labels and more by how functional impairment is interpreted, operationalized, and translated within school contexts. Apparent disagreement between clinic and school eligibility decisions

was most strongly associated with severity of CNS dysfunction rather than FASD diagnostic category, underscoring the primacy of functional impact in school-based eligibility determinations. At the same time, the higher rates of IEP match observed for students with ND/AE suggest that alignment may be facilitated when clinical profiles align with familiar school-based frameworks, even when the complexity of PAE is not fully articulated.

Apparent mismatch at a single point in time may reflect the timing of evaluations, delays in school-based response, or limited opportunities to revisit educational plans following diagnosis. Conversely, apparent “match” does not necessarily indicate adequacy of services. These findings support the need to view educational planning for students with FASDs as an ongoing, developmentally responsive process rather than a fixed correspondence between documents. From a school psychology perspective, these findings align closely with the principles of early intervention and MTSS, emphasized in the broader literature. MTSS frameworks prioritize early identification, data-based decision-making, progress monitoring, and responsiveness to intervention—elements that are particularly critical for students with FASDs, whose needs may be cross-domain and vulnerable to under-identification. The high proportion of students without preexisting IEPs who were nevertheless recommended for formal evaluation or supports highlights the importance of proactive, tiered approaches to identification and intervention, rather than reliance on categorical eligibility alone.

Across all phases of educational planning, school psychologists emerge as central agents in bridging clinic and school systems. As evaluators, consultants, and integral IEP team members, school psychologists are uniquely positioned to translate complex neurodevelopmental information—such as CNS severity, executive functioning vulnerabilities, and adaptive skill deficits—into educationally meaningful eligibility decisions, services, and accommodations. The

findings of this study suggest that alignment is strongest when clinical recommendations align with familiar educational frameworks and weakest when students present with cross-domain needs that require coordinated, interdisciplinary responses. This underscores the importance of training, consultation, and systems-level flexibility within school psychology practice.

In conclusion, this study advances the literature by integrating interdisciplinary FASD diagnostic evaluations with school-based IEP documentation to examine patterns of identification, alignment, and mismatch across systems. Findings demonstrate that alignment between clinical recommendations and educational programming is influenced more by functional CNS impairment and system familiarity than by diagnostic label alone. These results highlight persistent gaps in the translation of neurodevelopmental knowledge into school-based planning for some students with FASDs, while also illustrating the potential for strong alignment when functional needs are clearly articulated and operationalized. By centering the role of school psychologists within MTSS and early intervention frameworks, this work underscores the profession's critical responsibility in translating clinical information into educationally meaningful language and ensuring that planning for students with FASDs is timely, developmentally responsive, and grounded in a comprehensive understanding of neurodevelopmental need.

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Tables

Table 1. Matrix for Organizing Qualitative Data

Research Question	Data Source (n=15)		Comments
What are the content differences between clinical diagnostic evaluation reports and school-based IEPs for children with FASD in terms of: • Diagnosis • Recommended interventions • Consideration of functional domains (e.g., executive functioning) ➔ Code presence/absence and detail level for each domain (e.g., 0 = not present, 1 = vague mention, 2 = clearly described) ➔ Qualitative info as well with quotes/explain percentages	• IEP_004 • IEP_007 • IEP_009 • IEP_011 • IEP_024 • IEP_026 • IEP_027 • IEP_036 • IEP_040 • IEP_060 • IEP_061 • IEP_062 • IEP_066 • IEP_068 • IEP_072	• Clin_004 • Clin_007 • Clin_009 • Clin_011 • Clin_024 • Clin_026 • Clin_027 • Clin_036 • Clin_040 • Clin_060 • Clin_061 • Clin_062 • Clin_066 • Clin_068 • Clin_072	1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15.
What are most common areas of misalignment between clinical and IEP documentation for: • Eligibility category • Intervention/Accommodation dosage, frequency, and provider • Instructional approach alignment (e.g., behavioral supports, accommodations) 0=match 1=some mismatch (1) 2=high mismatch (2+)	• IEP_004 • IEP_007 • IEP_009 • IEP_011 • IEP_024 • IEP_026 • IEP_027 • IEP_036 • IEP_040 • IEP_060 • IEP_061 • IEP_062 • IEP_066 • IEP_068 • IEP_072	• Clin_004 • Clin_007 • Clin_009 • Clin_011 • Clin_024 • Clin_026 • Clin_027 • Clin_036 • Clin_040 • Clin_060 • Clin_061 • Clin_062 • Clin_066 • Clin_068 • Clin_072	1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15.

How well do recommendations in the clinical report match the documented needs of the child in their IEP?	• IEP_004 • IEP_007 • IEP_009 • IEP_011 • IEP_024 • IEP_026 • IEP_027 • IEP_036 • IEP_040 • IEP_060 • IEP_061 • IEP_062 • IEP_066 • IEP_068 • IEP_072	• Clin_004 • Clin_007 • Clin_009 • Clin_011 • Clin_024 • Clin_026 • Clin_027 • Clin_036 • Clin_040 • Clin_060 • Clin_061 • Clin_062 • Clin_066 • Clin_068 • Clin_072	1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15.
What questions do the reports still leave unanswered: • To what extent are the recommendations in each document actionable/feasible within school constraints (e.g., time during the school day, adequate staffing/provider)? • Did families bring FAS DPN report to school to be incorporated into IEP? • Were services and/or eligibility category changed after FAS DPN recommends?	• IEP_004 • IEP_007 • IEP_009 • IEP_011 • IEP_024 • IEP_026 • IEP_027 • IEP_036 • IEP_040 • IEP_060 • IEP_061 • IEP_062 • IEP_066 • IEP_068 • IEP_072	• Clin_004 • Clin_007 • Clin_009 • Clin_011 • Clin_024 • Clin_026 • Clin_027 • Clin_036 • Clin_040 • Clin_060 • Clin_061 • Clin_062 • Clin_066 • Clin_068 • Clin_072	1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15.

Table 2. Codebook for IEP and Clinical Documents

Code Name	Definition	Example
Formal Support-Continued	The patient currently has an IEP and the UW FAS DPN team agrees with continued support and services under an IEP.	"These challenges should continue to be supported through specialized instruction and appropriate accommodation through an individualized education plan (IEP)."
Formal Support-Establish	The patient does not currently have an IEP and the UW FAS DPN team recommends an IEP be pursued.	"_____ diagnoses of ADHD, and Sentinel Physical Findings/Static Encephalopathy/Alcohol-Exposed may qualify her for an IEP under the category of "Other Health Impairment."
Eligibility-Match	The patient's current special education disability eligibility category is appropriate given the results of the evaluation at UW FAS DPN and the child's diagnosis/diagnoses.	"_____'s current support is in the eligibility category of "Other Health Impaired." This continues to be appropriate based on his ADHD and his fetal alcohol spectrum disorder diagnosis."
Eligibility-Mismatch	The patient's current special education disability eligibility category is inappropriate given the results of the evaluation at UW FAS DPN and the child's diagnosis/diagnoses.	"Given the pattern of challenges, we would recommend that [PATIENT'S] IEP team change his eligibility criteria to the category of..."
Evidence-Based Intervention Named	A clearly named, research-based intervention or service	"A very structured approach to learning how to regulate emotional states and physical symptoms may be beneficial. The Zone of Regulation (http://zonesofregulation.com) approach uses visual supports

		and concrete strategies in teaching regulation skills.”
Generic Recommendation	A vague/confusing suggestion without a clear plan, goal, or intervention	“___ needs emotional support in the classroom.”
Needs-Intervention Match	The recommendation aligns with the documented disability or need	“___ demonstrated significant difficulties with fine motor control and the visual-motor aspects of writing. Working with the OT and educational team on accommodations for written expression (e.g., using a scribe and computer technology such as speech to text software) are recommended.”
Needs-Intervention Mismatch	The recommendation is not clearly documented as an identified need	“Tutoring in math” is reflected on IEP despite no math-related challenges identified in evaluation.
Feasibility Concern	Recommendations and intervention are not accessible due to cost, availability, or other barriers.	“Results from today’s assessment indicate a need for a more comprehensive psycho-educational evaluation to support _____ understanding of her learning profile and to support appropriate educational planning.”
Implementation Detail	Specifies how, when, or who will implement the recommendation	“SLP will provide 2x/week direct services in pull-out setting for 20-minutes.”
Lacks Implementation Plan	No clear indication of how/when/who will provide the intervention	“_____ would benefit from social skills.”

Table 3. Sociodemographics of the Study Population by Diagnostic Category

Sociodemographics	FASD Diagnosis			Total
	FAS (n = 3) n (%)	SE/AE (n=60) n (%)	ND/AE (n = 25) n (%)	N = 88 n (%)
Age at diagnosis				
8-10	1 (33%)	30 (50%)	11 (44%)	42 (48%)
11-14	2 (67%)	16 (27%)	9 (36%)	27 (31%)
15-18	0	14 (23%)	5 (20%)	19 (21%)
Caregiver Status				
Biological parent	1 (33%)	5 (8%)	3 (12%)	9 (10%)
Kinship	0	13 (22%)	4 (16%)	17 (19%)
Foster	0	5 (8%)	0	5 (6%)
Adopted	2 (67%)	36 (60%)	18 (72%)	56 (64%)
Case Worker	0	1 (2%)	0	1 (1%)
Race and Ethnicity				
White	1 (33%)	28 (47%)	8 (32%)	37 (42%)
Black	1 (33%)	6 (10%)	7 (28%)	14 (16%)
Native American/Alaskan Native	0	2 (3%)	0	2 (2%)
Hispanic/Latinx	0	5 (8%)	2 (8%)	7 (8%)
Asian	0	1 (2%)	0	1 (1%)
Native Hawaiian/Pacific Islander	0	5 (8%)	1 (4%)	6 (7%)
Multiracial	1 (33%)	13 (22%)	7 (28%)	21 (24%)
Sex Assigned at Birth				
Female	0	33 (67%)	16 (33%)	49 (56%)
Male	3 (8%)	27 (69%)	9 (23%)	39 (44%)
School Status				
Homeschooled	1 (33%)	7 (12%)	2 (8%)	10 (11%)
Not Homeschooled	2 (67%)	53 (88%)	23 (92%)	78 (89%)

Table 4. RQ1 and Hypothesis 1

Hypothesis 1: The majority (over 50%) of the study patients will have a preexisting IEP, given that many patients came to the clinic after demonstrated challenges in school and with previously diagnosed challenges.				
Preexisting IEP	FAS (n = 3)	SE/AE (n = 60)	ND/AE (n = 25)	Total (n = 88)
yes	2 (67%)	35 (58%)	8 (32%)	45 (51%)
no	1 (33%)	25 (42%)	17 (68%)	43 (49%)

Table 5. RQ2 and Hypothesis 2

Hypothesis 2: Study patients who were in a foster care placement, patients who were non-white, patients who were female, and patients who were homeschooled will be less likely to have a preexisting IEP.		
Demographic Variable	Preexisting IEP	
	Yes: 45	No: 43
In foster care at time of diagnosis		
Yes	4 (80%)	1 (20%)
No	41 (49%)	42 (50%)
Race		
nonWhite	23 (45%)	28 (55%)
White	22 (59%)	15 (41%)
Sex Assigned at Birth		
Female	23 (47%)	26 (53%)
Male	22 (56%)	17 (44%)
Homeschooled		
Yes	0 (0%)	10 (100%)
No	45 (58%)	33 (42%)

Table 6. RQ3 and Hypothesis 3

Hypothesis 3: Of the patients with a preexisting IEP, Other Health Impaired, Specific Learning Disability, and Emotional/Behavioral Disturbance will be the most common special education eligibility categories for patients who receive an FASD diagnosis, given symptom and challenge overlaps with these eligibility categories.				
Special Ed Eligibility Categories	FAS (n = 2)	SE/AE (n = 35)	ND/AE (n = 8)	Total (n = 45)
	n (%)	n (%)	n (%)	n (%)
Other Health Impaired	2 (100%)	22 (62%)	5 (17%)	29 (64%)
Specific Learning Disability	0	5 (14%)	1 (17%)	6 (13%)
Emotional/Behavioral Disturbance	0	2 (5%)	2 (5%)	4 (9%)
Developmental/Intellectual Disability	0	4 (11%)	0	4 (9%)
Multiple Disabilities	0	2 (5%)	0	2 (4%)
Autism Spectrum Disorder*	n/a	n/a	n/a	n/a
Deaf-Blindness	0	0	0	0
Deafness	0	0	0	0
Hearing impairment	0	0	0	0
Orthopedic impairment	0	0	0	0
Speech or Language Impairment	0	0	0	0
Traumatic Brain Injury	0	0	0	0
Visual impairment	0	0	0	0

Table 7a. RQ4 and Hypothesis 4

Hypothesis 4. Patients at the more severe end of the FASD spectrum (FAS and SE/AE) will have the highest prevalence of IEP eligibility category disagreement, with the clinic suggesting a change in eligibility category.				
IEP and Clinic Eligibility Alignment	FAS (n = 2)	SE/AE (n = 35)	ND/AE (n = 8)	Total (n = 45)
	n (%)	n (%)	n (%)	n (%)
Yes, clinic agrees with IEP eligibility category	2 (100%)	27 (77%)	6 (75%)	35 (78%)
No, clinic recommends change in eligibility category	0	8 (23%)	2 (25%)	10 (22%)

Table 7b.

Hypothesis 4a. Patients with the most severe CNS dysfunction (CNS Rank 3) will have the highest prevalence of IEP eligibility category disagreement.				
IEP and Clinic Eligibility Alignment	CNS Rank 1 (n = 0)	CNS Rank 2 (n = 7)	CNS Rank 3 (n = 38)	Total (n = 45)
	n (%)	n (%)	n (%)	n (%)
Yes, clinic agrees with IEP eligibility category	0	6 (86%)	29 (76%)	35 (78%)
No, clinic recommends change in eligibility category	0	1 (14%)	9 (24%)	10 (22%)

Note: FAS and SE/AE require severe brain dysfunction (CNS Rank 3: 3 or more domains of function 2 or more SDs below the mean. CNS Rank 1: no evidence of brain dysfunction. CNS Rank 2: 1 or 2 domains of brain function are 2 or more SDs below the mean).

Table 8a. RQ5 and Hypothesis 5

Hypothesis 5. Patients with ND/AE will be more likely than patients with FAS or SE/AE to have IEPs that do not match their needs.								
	FAS and SE/AE (n = 37)		ND/AE (n = 8)		Total (n=45)		Fisher's Exact Test	
IEP Matches Needs	n	%	n	%	n	%	Test	p-value
Yes	6	16%	5	62%	11	24%	Fisher's Exact	<i>p</i> = .014
No	31	83%	3	38%	34	76%		

Table 8b. RQ5 and Hypothesis 5

(slightly expanded) Hypothesis 5. Patients with ND/AE will be more likely than patients with FAS or SE/AE to have IEPs that do not match their needs.						
	FAS and SE/AE (n = 37)		ND/AE (n = 8)		Total (n=45)	
IEP Matches Needs	n	%	n	%	n	%
Matches / No mismatch	6	16%	5	62%	11	24%
Some Mismatch (1 area)	18	49%	1	13%	19	42%
High Mismatch (2+ areas)	13	35%	2	25%	15	33%

Table 9. RQ5 and Hypothesis 5 expanded

(expanded) Hypothesis 5. Patients with ND/AE will be more likely than patients with FAS or SE/AE to have IEPs that do not match their needs.						
IEP matches needs	FAS and SE/AE (n = 37)		ND/AE (n = 8)		Total (n=45)	
	n	%	n	%	n	%
Yes, fully – no services added	6	16%	5	63%	11	24%
Yes, partially – OT added or changed	23	62%	1	13%	24	53%
Yes, partially – SLP added or changed	4	11%	0	0%	4	9%
Yes, partially – Transition Plan added	10	27%	2	25%	12	27%
No – clinic disagrees with eligibility category for services	8	22%	2	25%	10	22%

Table 10. Clinic Recommendations for Patients Without Preexisting IEPs

Mismatch for patients without IEP	FAS (n = 1)	SE/AE (n = 25)	ND/AE (n = 17)	Total (n = 43)
	n (%)	n (%)	n (%)	n (%)
No - patient does not have an IEP and clinic recommends a 504 Plan	0 (0%)	7 (28%)	10 (58%)	17 (40%)
No - child does not have an IEP, has a 504, clinic recommends IEP evaluation for further support	0 (0%)	4 (16%)	3 (18%)	7 (16%)
No – child does not have an IEP, clinic recommends comprehensive psychoeducational evaluation/IEP to determine needs	1 (100%)	23 (92%)	10 (59%)	34 (79%)
No - Clinic does not recommend IEP or 504 Plan, “close monitoring”	0 (0%)	0 (0%)	3 (17%)	3 (7%)

Note: Because the clinic team sometimes made concurrent recommendations for a 504 Plan and psychoeducational evaluation/IEP, totals across recommendation categories exceed the number of patients without an IEP (n = 43). Percentages within diagnostic groups therefore represent the proportion of patients in each category who received each type of recommendation, not mutually exclusive frequencies.

Table 11a. Patients with ADHD Diagnosis.

What proportion of patients have an ADHD diagnosis?				
ADHD Diagnosis	FAS (n = 3)	SE/AE (n = 60)	ND/AE (n = 25)	Total (n = 88)
yes	2 (67%)	45 (75%)	15 (60%)	62 (70%)
no	1 (33%)	15 (25%)	10 (40%)	26 (30%)

Table 11b. Patients with ADHD Diagnosis.

What was the most common eligibility category for patients with an ADHD diagnosis and an IEP?	
Eligibility Category	ADHD (n = 38)
Other Health Impaired	25 (65%)
Emotional/Behavioral Disturbance	4 (11%)
Developmental/Intellectual Disability	3 (8%)
Specific Learning Disability	5 (13%)
*Multiple Disabilities	1 (3%)

*Note: Multiple Disabilities for this patient were defined as OHI being primary and EBD being secondary.

Table 11c. Patients with ADHD Diagnosis.

What proportion of patients with an ADHD diagnosis and no IEP are recommended to get an IEP?	
Clinic Recommends IEP	ADHD & no IEP (n = 24)
Yes	20 (83%)
No	4 (17%)

Table 12. Implications of FASD-Related IEP Alignment Findings for School Psychology Practice

Finding	Interpretation	Implications for School Psychologists
Eligibility disagreement clustered by CNS severity, not diagnosis	Schools respond more to functional impairment than diagnostic labels	Emphasize CNS-related functional impacts (executive functioning, adaptive behavior, regulation) in eligibility evaluations and reports
FAS showed high eligibility agreement	Clear, “recognizable” profiles reduce ambiguity	Use FAS cases as exemplars for interdisciplinary alignment and training
ND/AE students showed higher IEP match	Familiar profiles align with existing service models	Critically evaluate whether “match” reflects adequacy or default service patterns
FAS and SE/AE showed partial or multi-domain mismatch	Diffuse needs exceed discrete service structures	Advocate for integrated, cross-disciplinary IEP planning
Clinical recommendations exceeded school documentation	Translation gap between clinic and school systems	School psychologists act as translators between neurodevelopmental findings and educational planning

Figures

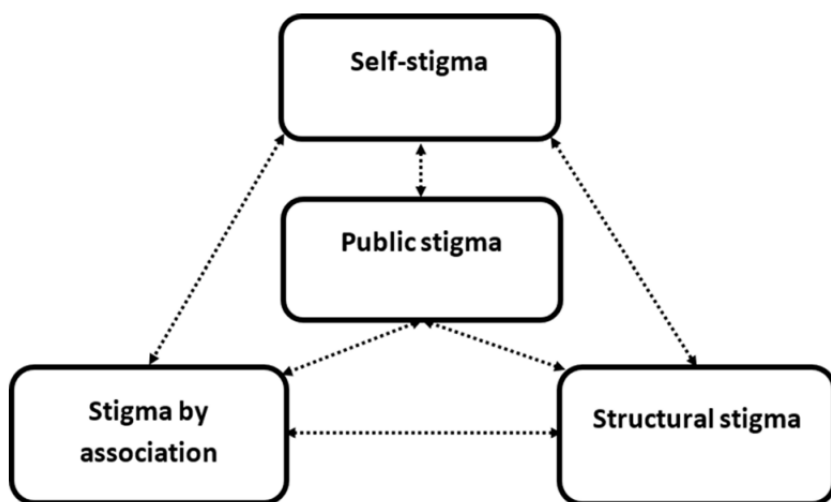
Figure 1. Types of Stigma, as cited in Roozen et al. (2022)

Figure 2. Descriptive Model of Stigma for FASD, as developed by Bell et al. (2016)

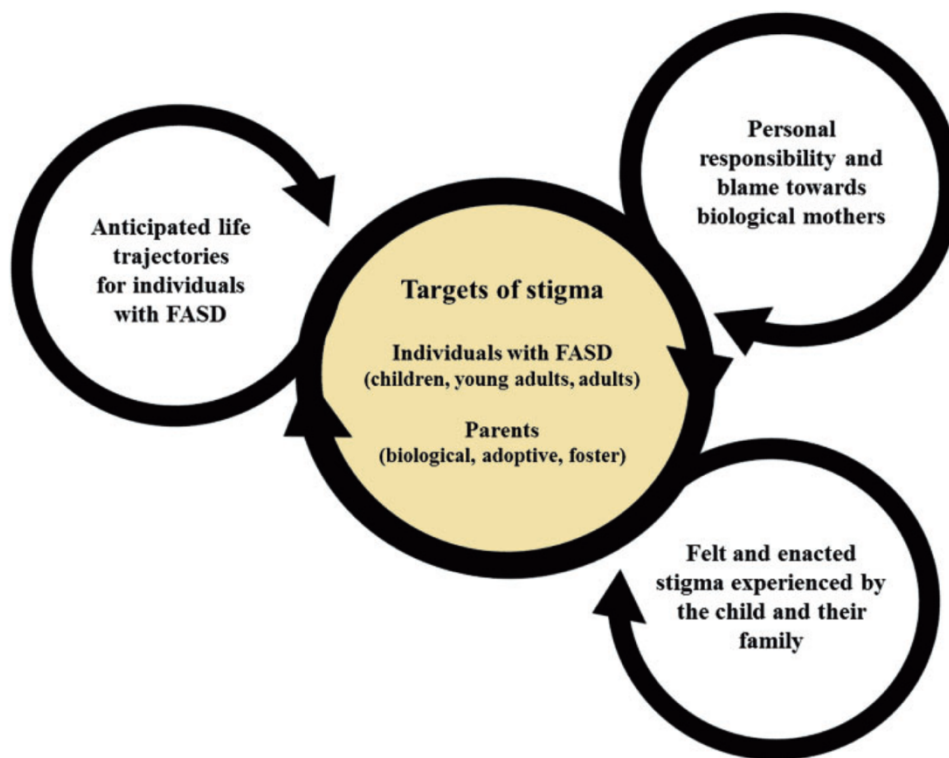
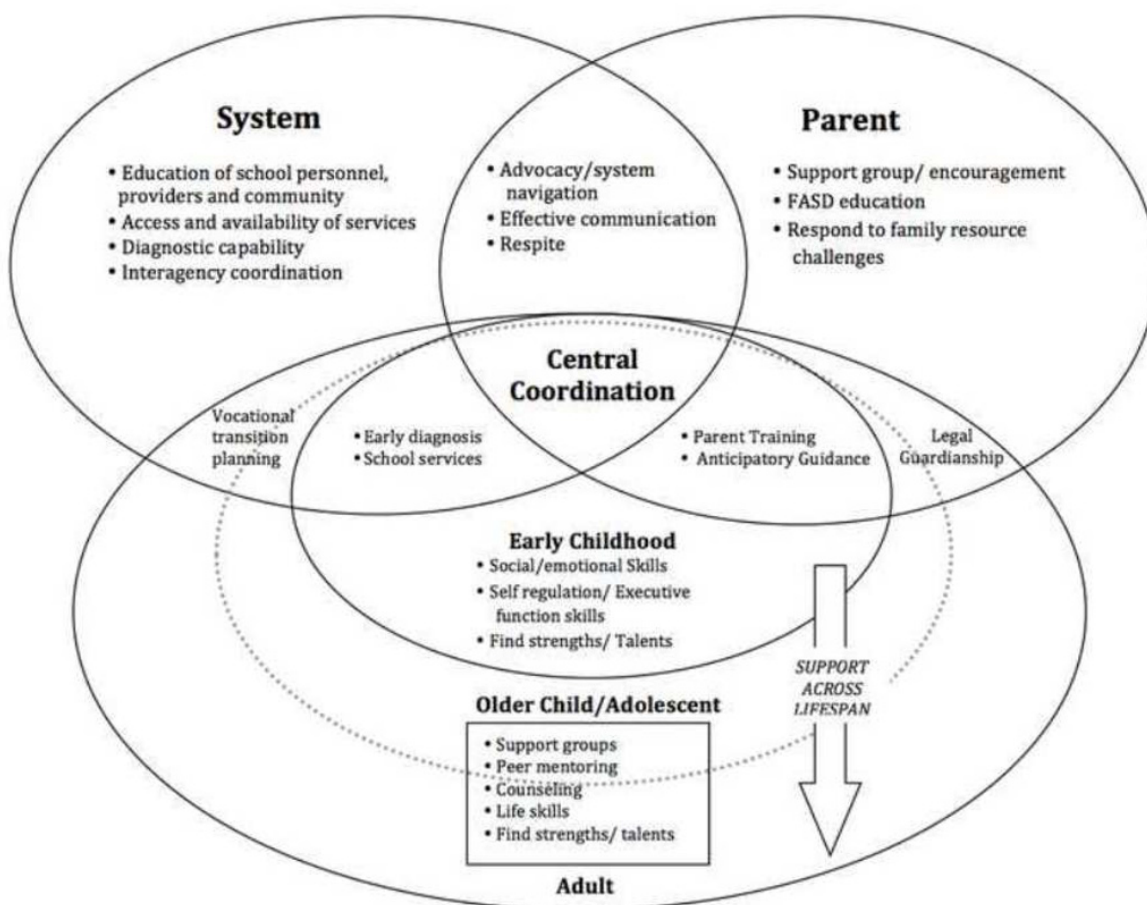


Figure 3. Lived experience model (Petrenko, 2015)



Lived experience model of identified program characteristics and specific intervention strategies for the prevention of secondary conditions in individuals with FASDs as cited in Petrenko (2015).

Figure 4. Evaluation process for typical evaluation day at UW FAS DPN

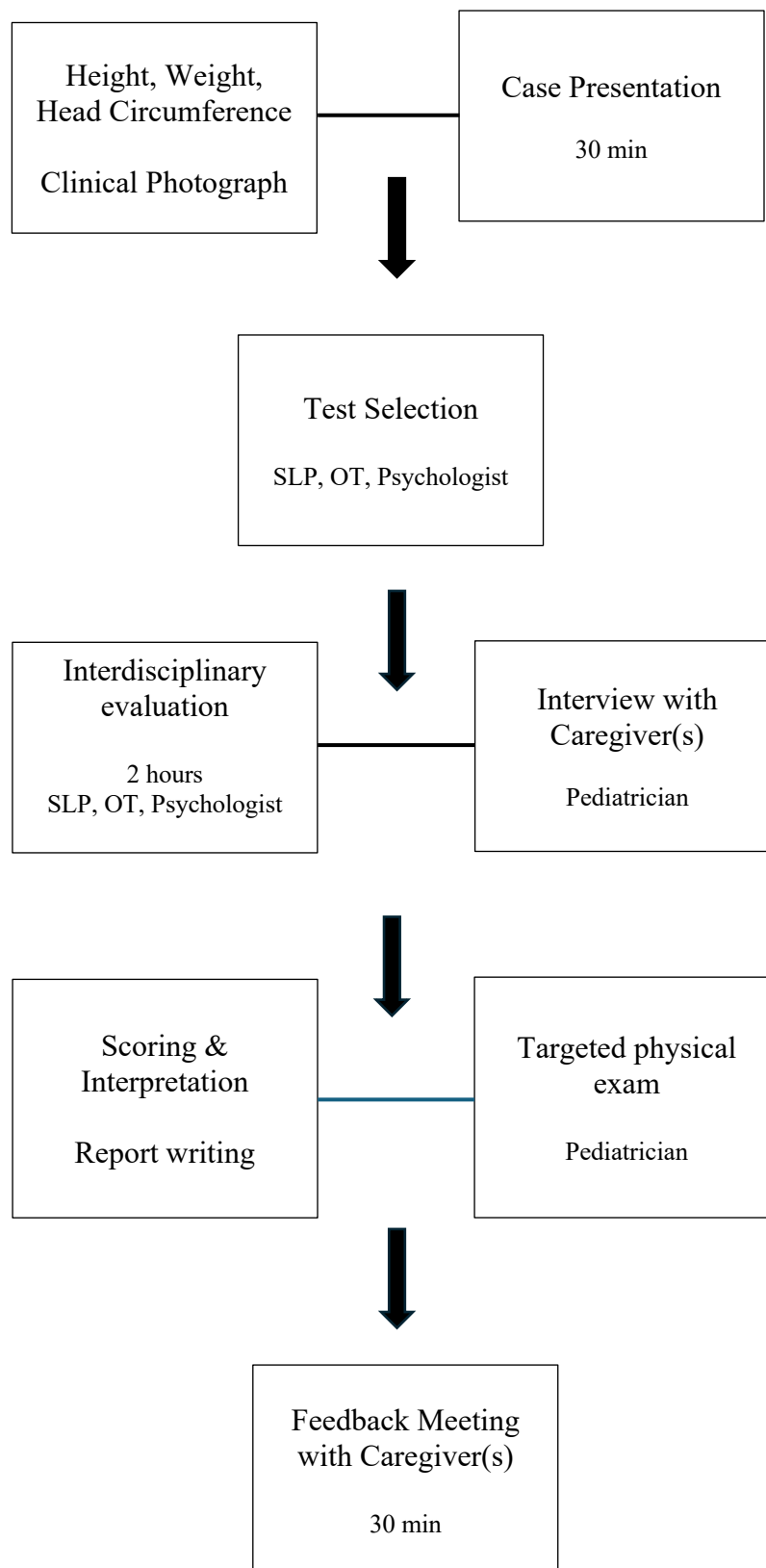


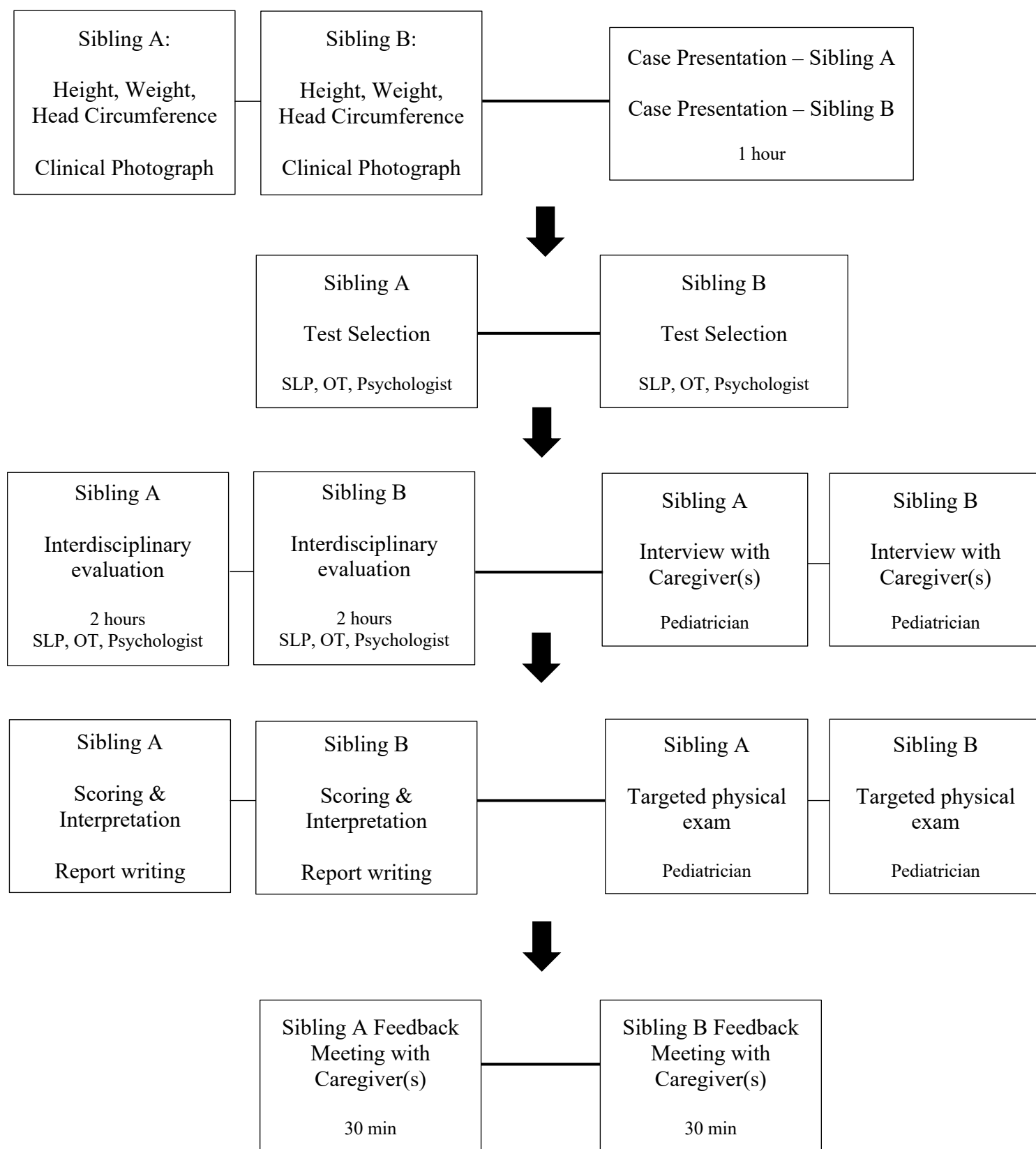
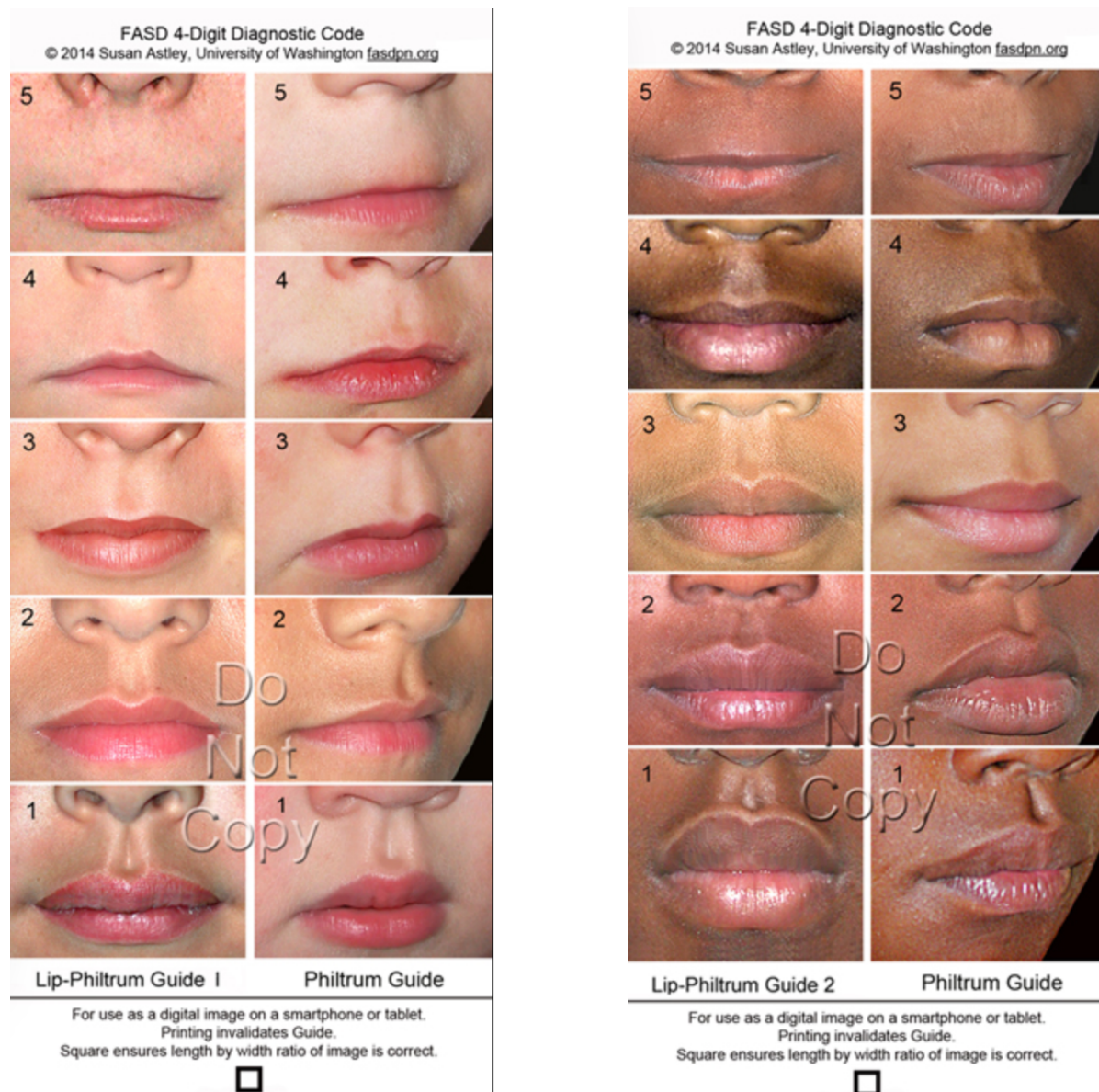
Figure 5. Evaluation process for sibling evaluation day at UW FAS DPN

Figure 6. Lip-Philtrum Guide 1 and Lip-Philtrum Guide 2



Lip-Philtrum Guide images provided with permission from Susan (Astley) Hemingway, Ph.D.

Figure 7. Lip-Philtrum Guide Backside

Caucasian Guide (Guide 1)

Guide 1 Tables

Lip Circularity		
Lip Rank	Pictured	Range
5	178	≥ 131.5
4	85	75.5 to 131.4
3	65	57.5 to 75.4
2	50	42.5 to 57.4
1	35	≤ 42.4

FACE TABLES				
5-Point Rank for Philtrum or Lip	Z-scores for Palpebral Fissure Length	ABC-Scores for:		
		Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
		CCA, CAC, CBB, CBA, CAB, CAA
		BCB, BCA, BBC, BAC
		ACC, ACB, ACA, ABC, AAC
2	Mild	
		BBB, BBA, BAB, BAA
		ABB, ABA, AAB, AAA
1	None	

GROWTH TABLES		
Percentile Range	ABC-Scores for:	
	Height	Weight
≤ 3rd	C	C
> 3rd and ≤ 10th	B	B
> 10th	A	A

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	Moderate	CB, BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

University of Washington FAS Diagnostic & Prevention Network
Astley, 2004

African American Guide (Guide 2)

Guide 2 Tables

FACE TABLES					
5-Point Rank for Philtrum or Lip	Z-score for Palpebral Fissure Length		ABC-Scores for:		
			Palpebral Fissure	Philtrum	Upper Lip
	4 or 5	≤ - 2 SD	C	C	C
	3	> -2 SD and ≤ -1 SD	B	B	B
	1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
		CCA, CAC, CBB, CBA, CAB, CAA
		BCB, BCA, BBC, BAC
		ACC, ACB, ACA, ABC, AAC
2	Mild	
		BBB, BBA, BAB, BAA
		ABB, ABA, AAB, AAA
1	None	

GROWTH TABLES			
Percentile Range	ABC-Scores for:		
	Height	Weight	
	≤ 3rd	C	C
	> 3rd and ≤ 10th	B	B
	> 10th	A	A

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	Moderate	CB, BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

University of Washington FAS Diagnostic & Prevention Network
Astley, 2004

lipguides2004-backside.doc

Susan Astley, University of Washington, FAS DPN

Tables provided with permission from Susan (Astley) Hemingway, Ph.D.

FACIAL FEATURES (and other physical findings)**CURRENT PHENOTYPE** Age _____ years Date ____/____/____**Direct Measures by Hand**

	mm	z-score	Normal Chart Used
Left PFL			
Right PFL			
Mean PFL			
Inner Canthal Distance			

5-Point Rank

UW Lip-Philtrum Guide Used

Philtrum		
Upper Lip		

2D Photograph or 3D Image

Frontal digital photo filename	Internal measure of scale (dot on forehead)		
	True dot size	Units (mm, cm, inches)	Dot size in photo, pixels

	Length in photo (pixels)	mm	z-score	Normal Chart Used
Left PFL				
Right PFL				
Mean PFL				
Inner Canthal Distance				

Photo filename	5-Point Rank	UW Lip-Philtrum Guide	
	Philtrum		Upper Lip Circularity
	Upper Lip		

PAST PHENOTYPE Age _____ years Date ____/____/____

Source of Information	Internal measure of scale (dot on forehead)		
	True dot size	Units (mm, cm, inches)	Dot size in photo (pixels)
Photo:			
Text Record:			

	Length in photo (pixel)	mm	z-score	Normal Chart Used
Left PFL				
Right PFL				
Mean PFL				
Inner Canthal Distance				

Photo filename	5-Point Rank	UW Lip-Philtrum Guide	
	Philtrum		Upper Lip Circularity
	Upper Lip		

FACIAL ABC-SCORE

See instructions in the "Diagnostic Guide for FASD" for deriving the ABC Score and 4-Digit Code

5-Point Likert Rank for Philtrum & Lip	Z-score for Palpebral Fissure Length	Circle the ABC Scores for:		
		Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	>-2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A
Source of Data for each Facial Feature →				

OTHER PHYSICAL FINDINGS / ANOMALIES / SYNDROMES / MEDICAL CONDITIONS

p 2 of 9

BRAIN

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
 Circle: 0 = Unknown, Not Assessed 1 = Within Normal Limits 2 = Mild to Moderate 3 = Severe

Severity	STRUCTURAL									
0 1 2 3	OFC	cm	smallest %tile	date	cm	%tile	date	cm	%tile	date

0 1 2 3 Structural anomalies seen on brain imaging: _____
 0 1 2 3 Other: _____

NEUROLOGICAL

0 1 2 3 Seizures: type: _____ meds. _____ Date of onset _____
 0 1 2 3 Other neurological signs (vision, hearing, tics, tremors): _____

FUNCTIONAL/Standardized Measures *Document most recent, valid test scores.*

0 1 2 3 **Cognition** (e.g., WISC, WAIS, DAS, TONI, Stanford-Binet, etc.)

0 1 2 3 **Processing Speed** (e.g., WISC, etc.)

Other Test/Subtest Names	Score	Type of Score	Date	Other Test/Subtest Names	Score	Type of Score	Date

0 1 2 3 **Academic Achievement** (e.g., WIAT, Woodcock Johnson, WRAT, Keymath, etc.)

Test/Subtest Name	Score	Type of Score	Date	Test/Subtest Name	Score	Type of Score	Date

0 1 2 3 **Adaptive Behavior / Social Skills** (e.g., VABS, BASC, ABAS, etc.)

Test/Subtest Name	Score	Type of Score	Date	Test/Subtest Name	Score	Type of Score	Date

BRAIN (Continued)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)

Circle: 0 = Unknown, Not Assessed 1 = Within Normal Limits 2 = Mild to Moderate 3 = Severe

Severity

0	1	2	3	Executive Function (e.g., D-KEFS, Rey Complex Figure Test, WCST, NEPSY, etc.)
---	---	---	---	--

[illegible]

0	1	2	3	Memory (CVLT, WRAML, Rey Complex Figure Test, etc)
---	---	---	---	---

[illegible]

0	1	2	3	Motor (e.g., PDMS, QNST, VMI, Brunuinks-Oseretsky Scales of Motor Dev, etc.)
---	---	---	---	---

0 1 2 3 **Sensory** (e.g., SSP, AASP, etc.)

[illegible]0 1 2 3 **Language** (e.g., TOLD, PLS, CELF, TOWL etc.)0 1 2 3 **Social Communication** (e.g., SCQ etc.)

0 1 2 3 **Speech Articulation** (Arizona, etc.)

[illegible]

Page 4 of 9

BRAIN (Continued)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)

Circle: 0 = Unknown, Not Assessed 1 = Within Normal Limits 2 = Mild to Moderate 3 = Severe

Severity

0 1 2 3 **Mental Health/Psychiatric Conditions:** (e.g., ADHD, ODD, Maj. Depression, ASD, etc)

<i>Disorder</i>	<i>Date Diagnosed</i>	<i>Disorder</i>	<i>Date Diagnosed</i>	<i>Disorder</i>	<i>Date Diagnosed</i>

<i>Medication. ✓ if Currently Taking</i>	<i>Response (+, -, none)</i>	<i>Medication. ✓ if Currently Taking</i>	<i>Response (+, -, none)</i>	<i>Medication. ✓ if Currently Taking</i>	<i>Response (+, -, none)</i>

0 1 2 3 **Behavior/Attention/Activity Level** (e.g., CBCL, Conners Rating Scale, NICHQ, BASC, CSHQ, etc.)

<i>Test/Subtest Name</i>	<i>Score</i>	<i>Type of Score</i>	<i>Date</i>	<i>Test/Subtest Name</i>	<i>Score</i>	<i>Type of Score</i>	<i>Date</i>

0 1 2 3 **Development** (e.g., Bayley Scales of Infant Dev., Battelle Dev. Invent., Miller Assessment of Preschoolers, etc.)

<i>Test/Subtest Name</i>	<i>Score</i>	<i>Type of Score</i>	<i>Date</i>	<i>Test/Subtest Name</i>	<i>Score</i>	<i>Type of Score</i>	<i>Date</i>

BRAIN (Continued)**FUNCTIONAL / Non-Standardized Observational Measures**

Severity Score: Severity of Delay/Impairment (Displayed along left margin)

Circle: 0 = Unknown, Not Assessed, Too Young 1 = Within Normal Limits 2 = Mild to Moderate 3 = Severe

Severity	Caregiver Interview
	Planning / Temporal Skills
0 1 2 3	Needs considerable help organizing daily tasks _____
0 1 2 3	Can not organize time _____
0 1 2 3	Does not understand concept of time _____
0 1 2 3	Difficulty in carrying out multi-step tasks _____
0 1 2 3	Other _____
	Behavioral Regulation/ Sensory Motor Integration
0 1 2 3	Poor management of anger / tantrums _____
0 1 2 3	Mood swings _____
0 1 2 3	Impulsive _____
0 1 2 3	Compulsive _____
0 1 2 3	Perseverative _____
0 1 2 3	Inattentive _____
0 1 2 3	Inappropriately [high or low] activity level _____
0 1 2 3	Lying/stealing _____
0 1 2 3	Unusual [high or low] reactivity to [sound touch light] _____
0 1 2 3	Other _____
	Abstract Thinking / Judgment
0 1 2 3	Poor judgment _____
0 1 2 3	Cannot be left alone _____
0 1 2 3	Concrete, unable to think abstractly _____
0 1 2 3	Other _____
	Memory / Learning / Information Processing
0 1 2 3	Poor memory, inconsistent retrieval of learned information _____
0 1 2 3	Slow to learn new skills _____
0 1 2 3	Does not seem to learn from past experiences _____
0 1 2 3	Problems recognizing consequences of actions _____
0 1 2 3	Problems with information processing speed and accuracy _____
0 1 2 3	Other _____
	Spatial Skills and Spatial Memory
0 1 2 3	Gets lost easily, has difficulty navigating from point A to point B _____
0 1 2 3	Other _____
	Social Skills and Adaptive Behavior
0 1 2 3	Behaves at a level notably younger than chronological age _____
0 1 2 3	Poor social/adaptive skills _____
0 1 2 3	Other _____
	Motor/Oral Motor Control
0 1 2 3	Poor/delayed motor skills _____
0 1 2 3	Poor balance _____
0 1 2 3	Other _____

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Diagnostic Form, Section II

4-Digit Code Diagnostic Guide for FASD (Astley Hemingway)

BRAIN (Continued)**FUNCTIONAL DOMAINS**

Examples include, but are not limited to Memory, Cognition, Language, Executive Function, Motor, and Attention.

Severity Score: Severity of Delay/Impairment (Displayed along left margin)

Circle: 0 = Unknown, Not Assessed 1 = Within Normal Limits 2 = Mild to Moderate 3 = Severe

Severity		
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	

See the "Diagnostic Guide for FASD" for instructions on deriving the 4-Digit Diagnostic Code for Brain

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MATERNAL ALCOHOL USE

Alcohol Consumption of the Birth Mother

Before Pregnancy	average number of drinks per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of drinking days per week:					
	Type(s) of alcohol	wine	beer	liquor	unknown	Other (specify)

During Pregnancy	average number of drinks per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of drinking days per week:					
	Type(s) of alcohol	wine	beer	liquor	unknown	Other (specify)

Trimester(s) in which alcohol was consumed	1 st	2 nd	3 rd	unknown	none
Was the birth mother ever reported to have a problem with alcohol?	yes	suspected	no	unknown	
Was the birth mother ever diagnosed with alcoholism?	yes	suspected	no	unknown	
Did the birth mother ever receive treatment for alcohol addiction?	yes	suspected	no	unknown	
Was alcohol use during this pregnancy positively confirmed through verbal or written documentation?	yes	no			
If yes, source of verbal or written confirmation:					
Reported use of alcohol during this pregnancy is:	Reliable	Somewhat reliable	Unk. reliability		
Was the Rank 4 FAS facial phenotype used as a proxy measure of prenatal alcohol exposure?	yes	no			
Other information about alcohol use during this pregnancy					

4-DIGIT RANK for Alcohol Exposure

4-Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description
4	High Risk	● Alcohol use during pregnancy is CONFIRMED. <i>and</i> ● Reported exposure pattern is consistent with the medical literature placing the fetus at "high risk" (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy, reports of intoxication, binge-drinking).
3	Some Risk	● Alcohol use during pregnancy is CONFIRMED. <i>and</i> ● Level of alcohol use is reported to be less than in Rank (4) or the level is unknown.
2	Unknown Risk	● Alcohol use during pregnancy is UNKNOWN (cannot be confirmed or ruled-out).
1	No Risk	● Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

Circle the 4-Digit Diagnostic Rank in the table above that best reflects the patient's Prenatal Alcohol Exposure

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OTHER PRENATAL AND POSTNATAL RISK FACTORS

PRENATAL RISKS:

No known risk	Unknown risk	Some risk	High risk
1	2	3	4

See the "Diagnostic Guide for FASD" for instructions on deriving the rank for Other Prenatal Risks.

Prenatal:

1. Parity ____, Gravity ____ of this birth. Birth order if child is the result of a multiple birth pregnancy: ____ of ____
2. Prenatal care: ____ Yes, (If yes, when did it start? _____), ____ No, ____ Unknown
3. Complications (specify) _____

Genetics

1. Biological parents learning difficulties
Mother ____ Yes ____ Suspected ____ No ____ Unknown. **Father** ____ Yes ____ Suspected ____ No ____ Unknown
2. Other conditions of heritability (ADHD, mental health, syndromes, etc.) that may be relevant to this case. (*specify*) _____

Prenatal Exposure to Other Substances (e.g., medications, tobacco, illicit drugs, other teratogens, etc.)

POSTNATAL RISKS:

No known risk	Unknown risk	Some risk	High risk
1	2	3	4

See the "Diagnostic Guide for FASD" for instructions on deriving the rank for Postnatal Risks.

Perinatal Difficulties (prematurity, extended stay in birth hospital, etc.): _____

Medical Conditions: _____

Postnatal Adversity (ACES, TESI, etc):

1. Number of out-of-home placements ____ Age at first out-of-home placement ____ Age at last placement ____
2. Please report the age range for all adversities experienced by the patient. If age is unknown, enter Yes, No Suspected or Unknown in each box.

Adversity	age range	Adversity	age range	Adversity	age range
sexual abuse		orphanage/group care		serious medical issue	
physical abuse		abandonment		substance abuse (patient)	
emotional abuse		homelessness		patient incarceration	
domestic violence		poverty		patient suicide attempt	
physical neglect		food insecurity		natural disaster	
emotional neglect		bullying		war, terrorism	
medical neglect		school violence		List others below	
family death		community violence			
family incarceration		discrimination			
parent separated/divorced		serious accident			
family mental health		home fire			
parent substance abuse		animal attack			

Additional details that may be relevant:

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FASD 4-Digit Diagnostic Code – Short Form 2024

In lieu of using the 9-page comprehensive Diagnostic Form presented above, this 1-page Short Form documents all pertinent information needed to derive/support the patient's 4-Digit Code. An electronic version of the form is available on the [FASDPN website](#).

FASD 4-Digit Diagnostic Code – Short Form (2024)																																																														
*(Astley) Hemingway SJ, Diagnostic Guide for FASD: The 4-Digit Code, 4th ed. 2024																																																														
Patient Name					Birth date																																																									
Sex/Gender					Clinic Date																																																									
Race					Age (yrs)																																																									
Clinic Name					Medical #																																																									
NAME OF DIAGNOSIS			FASD 4-DIGIT DIAGNOSTIC CODE																																																											
			<table border="1" style="width: 100%; border-collapse: collapse; text-align: center;"> <tr> <th>Rank</th> <th>severe</th> <th>all 3 features</th> <th>abnormal structure/neurology</th> <th>high</th> <th>high</th> <th>high</th> </tr> <tr> <td>4</td> <td>severe</td> <td>all 3 features</td> <td>abnormal structure/neurology</td> <td>high</td> <td>high</td> <td>high</td> </tr> <tr> <td>3</td> <td>moderate</td> <td>2-5 features</td> <td>severe dysfunction</td> <td>some</td> <td>some</td> <td>some</td> </tr> <tr> <td>2</td> <td>mild</td> <td>1-2 features</td> <td>moderate dysfunction</td> <td>unknown</td> <td>unknown</td> <td>unknown</td> </tr> <tr> <td>1</td> <td>normal</td> <td>no features</td> <td>normal function</td> <td>none</td> <td>none</td> <td>none</td> </tr> </table>							Rank	severe	all 3 features	abnormal structure/neurology	high	high	high	4	severe	all 3 features	abnormal structure/neurology	high	high	high	3	moderate	2-5 features	severe dysfunction	some	some	some	2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown	1	normal	no features	normal function	none	none	none																		
			Rank	severe	all 3 features	abnormal structure/neurology	high	high	high																																																					
			4	severe	all 3 features	abnormal structure/neurology	high	high	high																																																					
			3	moderate	2-5 features	severe dysfunction	some	some	some																																																					
			2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown																																																					
1	normal	no features	normal function	none	none	none																																																								
Growth		Face		Brain		Prenatal Alcohol		Other Prenatal Risks																																																						
DATA BELOW WAS USED TO DERIVE / SUPPORT 4-DIGIT CODE																																																														
GROWTH					GROWTH TABLES (Circle ABC Scores to Derive Rank)																																																									
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Appendix B

FAS Facial Photographic Analysis Report

IDENTIFICATION			
Name	John T Doe		
	First Middle Last		
	Subject I.D.	None	
	Source of Photo	Clinic	
	Gender	Male	
	Race	Caucasian/Caucasian	
	Birth Date	1/1/1990	

PHOTO ASSESSMENT			
Normal PFL Chart: <u>Scandinavian (Stromland '99)</u>		Lip-Philtrum Guide: <u>Caucasian</u>	
Normal ICD Chart: <u>Caucasian (Hall '89)</u>		Frontal	¾ View
			Lateral
File Name	Demo Frontal	Demo 3/4	Demo Lateral
Date of Photo	6/22/1998	6/22/1998	6/22/1998
Age (yrs) in photo	8.47	8.47	8.47
Date of Photo Assessment	6/22/1998	6/22/1998	6/22/1998
Photo Assessor	Astley	Astley	Astley
Length of Real Internal Measure of Scale(sticker) placed on forehead (mm)			19.05
Length of Internal Measure of Scale in Frontal Photo (pixels)			155.2
Left Palpebral Fissure Length:	In photo (pixels) <u>208.5</u>	True Length (mm) <u>28.2</u>	Z-score <u>1.04</u>
Right Palpebral Fissure Length:	In photo (pixels) <u>205.5</u>	True Length (mm) <u>27.7</u>	Z-score <u>0.67</u>
Mean Palpebral Fissure Length:	In photo (pixels) <u>207.0</u>	True Length (mm) <u>28.0</u>	Z-score <u>0.86</u>
Inner Canthal Distance (ICD):	In photo (pixels) <u>200.0</u>	True Distance (mm) <u>24.5</u>	Z-score <u>-2.24</u>
Flat Philtrum (5-point rank):		In Frontal Photo <u>3</u>	In ¾ Photo <u>3</u>
Thin Upper Lip:	Circularity (perimeter²/area) <u>44.2</u>	5-Point rank (Circ) <u>2</u>	5-Point rank (Scale) <u>2</u>
down eyebrows ☐ ptosis ☐ strabismus ☐ epicanthal folds ☒			
flat midface ☐ protruding ears ☐ flat nasal bridge ☐ hypertelorism ☐			
Other anomalies present: <u>hypotelorism</u>			
Comments:			
Other syndromes present: <u>None reported</u>			

PHOTO QUALITY			
	Frontal	¾ View	Lateral
Side showing		Right	Left
Head rotation (5-point rank/degrees) to subject's Right (+) or Left (-)	<u>0°</u>	<u>0</u>	<u>0</u>
Head tilt (5-point rank) toward subject's Right (+) or Left (-) shoulder			
Head tip (degrees) Up (+) or Down (-) from Frankfort Horizontal Plane	<u>0°</u>		
Exposure (3-point rank)	<u>1 (good)</u>	<u>1 (good)</u>	<u>1 (good)</u>
Focus (3-point rank)	<u>1 (good)</u>	<u>1 (good)</u>	<u>1 (good)</u>
Facial Expression (3-point rank)			
Reliability of ABC-Score for palpebral fissure length (5-point rank)	<u>1 (very good)</u>		
Reliability of ABC-Score for philtrum (5-point rank)	<u>1 (very good)</u>	<u>1 (very good)</u>	
Reliability of ABC-Score for upper lip (5-point rank)	<u>1 (very good)</u>		

OUTCOME			
ABC-Score	A	B	A
	PFL	Philtrum	Lip
Data Used	mean	¾ view	circularity
4-Digit Diagnostic Code for Face <u>1: FAS features absent</u>			



Demo Frontal



Demo 3/4



Demo Lateral