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How Do Clinicians and Caregivers Describe Barriers to FASD Evaluation and Diagnosis?

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St. John's University

2021

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An abstract of

A thesis submitted to the Faculty of the

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Abstract

How Do Clinicians and Caregivers Describe Barriers to FASD Evaluation and Diagnosis?

By Jordan Hill-Rucker

FASD is a diagnosis that encompasses a range of developmental disabilities caused by prenatal alcohol exposure, such as neurological abnormalities and cognitive and behavioral impairment. Existing literature suggests that FASD occurs as often as autism spectrum disorder, but FASD remains underdiagnosed in most clinical settings. This phenomenon is deleterious to individuals who have FASD because diagnosis is needed for receipt of effective treatment of symptoms and interventions that mitigate harmful outcomes caused by the disorder, such as lifelong physical and cognitive disability, homelessness, imprisonment and other ramifications that lead to a poor quality of life for these individuals. Past research shows that various barriers, including social stigma and lack of awareness of FASD, contribute to the underascertainment of FASD. However, there was limited existing qualitative research that explored barriers to diagnosis of FASD and no qualitative study examined barriers to evaluation and diagnosis of FASD in the United States. This CDC sponsored study of the process of the evaluation and subsequent diagnosis of children increased qualitative evidence regarding barriers to timely FASD diagnosis by using semi-structured one-on-one interviews to identify and understand barriers to evaluation and diagnosis of FASD based on lived experiences of caregivers of children suspected of having FASD and clinicians who evaluate and diagnose children with FASD.

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Introduction

FASD is a diagnosis that encompasses a range of developmental disabilities caused by prenatal alcohol exposure (PAE), such as neurological abnormalities and cognitive and behavioral impairment.[1] It is comprised of five diagnoses, which include Fetal Alcohol Syndrome (FAS), partial FAS, Alcohol-Related Neurodevelopmental Disorder (ARND), Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE), and Alcohol-Related Birth Defects (ARBDs).[2] A recent study found that less than 1% of first graders who were categorized as having Fetal Alcohol Spectrum Disorder (FASD) had been diagnosed with FASD in the past.[3] Other studies have also concluded that FASD is significantly underdiagnosed.[4] Such studies imply that FASD occurs as often as autism spectrum disorder, but FASD remains underdiagnosed in most clinical settings.[4,5]

Significant variation exists regarding the estimated prevalence of FASD across geographic areas. The worldwide prevalence rate of FASD is estimated to be 0.77% and the European/North American prevalence rate is estimated to be 2-5%. These differences in prevalence rates result from differences in methodologies based on epidemiological method, country, differences in diagnostic criteria for FAS and FASD, geographical trends of drinking during pregnancy along with connected risk factors like maternal nutrition and prenatal care.[3,6] Additional variations in FASD prevalence rates have been found within the United States as exhibited by a study that assessed the prevalence of FASD in 4 communities across different regions in the United States and uncovered estimates of 11.3 to 50 per 1,000 births. In the unspecified southeastern county that was one of the 4 communities that were sampled for this study, one sample elicited a prevalence of 31.1 per 1,000 children while the other uncovered a prevalence of 66.8 per 1,000 children.[5] Children who are in foster care are distinctly at risk of

being diagnosed with FASD considering that many of these children are removed from homes because of parental substance use. An estimated 17% of children in the child welfare system may be impacted by FASD.[7] These differences in prevalence estimates between settings are perhaps attributed to diagnostic challenges.

Risk Factors of FASD

There are a number of reproductive circumstances that contribute to the serious risk of individuals developing FASD and FASD's significance as a public health issue. As mentioned previously, the main reproductive risk factor of FASD is PAE.[1] The first days that follow the initial missed menstrual cycle is when disruption of gastrulation and neurulation through alcohol may lead to the cardinal craniofacial features and brain abnormalities associated with FASD.[4,8] Considering that an estimated 7.3% of pregnancies involve exposure to alcohol according to self-reports,[9] the high prevalence of FASD mirrors the high rate of PAE.[10] The severity of the risk of developing FASD is compounded by binge drinking done by women who are of childbearing age being a problem around the world and the number of women who meet this criteria growing in certain countries.[11] For example, in the United States, BEHAVIORAL RISK FACTOR SURVEILLANCE system data analyzed by the CDC found that the prevalence of alcohol use in the past 30 days among nonpregnant women 18-44 years old increased from 51.5% between 2006 and 2010 to 53.6% from 2011 to 2013 and the prevalence of binge drinking among this demographic increased from 15% between 2006 and 2010 to 18.2% between 2011 and 2013. Among pregnant women, the prevalence of alcohol use in the past 30 days continued to increase from 7.6% between 2006 and 2010 to 13.5% between 2018 and 2020 while the prevalence of

binge drinking increased from 1.4% between 2006 and 2010 to 5.2% between 2018 and 2020.[12-14]

Consequences of FASD

FASD contributes to the development of many negative health and life outcomes for individuals who have the disorder. Meta-analyses that have analyzed FASD cohorts have uncovered striking growth in behavioral disturbance (i.e., a 8-10 fold increase of ADHD in comparison to population prevalence rates), intellectual impairment (a 97 fold increase), and anxiety disorders (a 11 fold increase).[15,16] In one cohort of clinically referred patients, adults who were 21-51 years old and had FASD, 90% had mental health issues, 60% experienced trouble with the law, and 45% experienced drug and alcohol problems.[17] Other adverse consequences that may arise for individuals who have FASD include secondary conditions such as coexisting medical conditions, lifelong physical and cognitive disability, social difficulties, reduced productivity, unemployment, homelessness, and imprisonment.[2,4,18,19]

Early Intervention is Paramount

Early identification of FASD is critical for diagnosis, effective treatment of symptoms, and prevention of harmful outcomes caused by the disorder. Initial clinical contact with FASD usually takes place during childhood,[18] which is a favorable period for diagnosis. Such early diagnosis, particularly before an individual is 6 years old, along with access to treatment may ameliorate adverse consequences of FASD through promotion of brain development and increase of the probability of developmental convergence.[17,18] Early identification and diagnosis of FASD

is also crucial considering that delayed FASD diagnosis has been linked to an increased risk of secondary disabilities, such as learning disabilities and disrupted school experience, socially unacceptable sexual behavior, and increased risk of substance use in the future.[17,20-23] Considering that FASD diagnosis is required to pinpoint co-morbid and co-occurring conditions and early diagnosis is needed to acquire necessary treatment and support services such as occupational support, housing and financial assistance, psychological treatments, and specialized legal counseling for individuals with the disorder;[24] timely diagnosis of FASD during childhood may be critical to mitigating the adverse impact of frequently co-occurring disabilities.

Known Barriers to Timely Diagnosis of FASD

However, a systematic under-ascertainment of FASD exists, which may be the result of social stigma, intricacy of diagnosis, dependance on facial features, and similarities with other conditions, including Attention Deficit Hyperactivity Disorder (ADHD) along with other challenges pertaining to the diagnostic processes.[1] For example, social stigma can inhibit clinicians from diagnosing children and caregivers from seeking a diagnosis. For clinicians, stigma can lead them to possibly attempt to safeguard a child affected by FASD from stigmatizing diagnostic labels in the healthcare system. This is influenced by clinicians mistakenly thinking that not designating the causes of the disorder impacting the child will be beneficial for the child's mental health and social adaptation.[25] Societal judgment can also cause mothers of children with FASD to hide that they consumed alcohol while they were pregnant.[26] Other factors that delay diagnosis of FASD are the lack of a definitive diagnostic assessment and universal diagnostic system, PAE confirmation, and lack of knowledge surrounding it.[1,24,27] The requirement of PAE confirmation is one of the most prominent obstacles to early and correct

diagnosis of FASD for affected children who do not possess the distinct facial features of FAS. It is especially difficult to obtain information regarding PAE for children who are in foster/adoptive care circumstances as a result of the absence of a biological caregiver when an evaluation is being performed.[24] The lack of knowledge pertaining to FASD is apparent via research finding that a large number of healthcare clinicians do not have sufficient training related to FASD,[28] which likely undermines their capability to identify signs of the disorder within individuals and appropriately diagnosing them. Moreover, adult neurologists are typically inexperienced in regard to FASD,[1] which may prevent them from diagnosing and appropriately providing care to adults who have FASD and further brings attention to the importance of diagnosis and treatment during childhood. Such barriers to diagnosis may obstruct care coordination for affected children and prevent receipt of necessary treatment for FASD symptoms, thus helping to prevent lifelong disability and poor quality of life into adulthood.[2,4,6]

This study applies qualitative methods to learn how clinicians and caregivers describe the barriers they experience with the diagnostic process and care coordination for children suspected of having or diagnosed with an FASD. Resulting evidence could potentially inform strategies to address obstacles to diagnosis and care coordination and in turn, aid amelioration of lifelong symptoms of the disorder among the target population and improve their quality of life.

Literature Review

Even as rates of alcohol consumption during pregnancy rise in the U.S., capacity to diagnose consequent fetal alcohol spectrum disorder (FASD) remains suboptimal. Analysis of BEHAVIORAL RISK FACTOR SURVEILLANCE system data by the CDC has revealed that the reported prevalence of past-30 day alcohol use among pregnant women increased from 7.6%

to 13.5% between 2006 and 2020; the prevalence of past-30 day binge drinking in this population increased from 1.4% to 5.2% during the same period.[12-14] This consumption can lead to FASD, which is characterized by birth defects, growth restriction, minor craniofacial anomalies, neurological abnormalities, and cognitive and behavioral impairment, and other harms.[1] A recent study quantified the magnitude of the underdiagnosis of FASD: the study screened all first graders in 4 study sites within diverse areas of the U.S. for FASD. Of those identified as meeting criteria for FASD, just 1% had been previously diagnosed.[3] Another project likewise assessed a sample of foster/adopted youth with behavioral issues for FASD and found that just 13.5% of those diagnosed by the project had been previously diagnosed with FASD.[4]

Left untreated, FASD is associated with higher rates of potentially lifelong health problems. Some health outcomes include lifelong physical and cognitive disability, behavioral disturbance, co-existing psychiatric and medical conditions, and reduced productivity.[19] Meta-analyses that have analyzed FASD cohorts have uncovered striking growth in behavioral disturbance (i.e., a 8-10 fold increase of ADHD in comparison to population prevalence rates), intellectual impairment (a 97 fold increase), and anxiety disorders (a 11 fold increase).[15,16] Past research using a clinically referred sample of adults who were 21-51 years old and had FASD, found that 90% had mental health issues, 60% experienced trouble with the law, and 45% experienced drug and alcohol problems.[17] Additionally, prevalence of FASD is high among people living in out-of-home care and or participating in justice and mental health systems.[29] Timely diagnosis of FASD (i.e., before an individual is 6 years old)[5] followed by effective treatment can ameliorate many of these harms through promotion of brain development and increase of the likelihood of developmental convergence.[17,18] Also, considering that FASD diagnosis is needed to acquire necessary treatment and support services such as occupational

support, housing and financial assistance, psychological treatments, and specialized legal counseling,[24] timely diagnosis of the disorder during childhood may be crucial for aiding prevention and mitigation of secondary disabilities among individuals living with FASD, including unemployment, homelessness, and imprisonment.[2,4]

However, FASD is systemically underdiagnosed. Underdiagnosis may be driven by social stigma, intricacy of diagnosis, dependance on facial features, and similarities with varying diagnoses, such as Attention Deficit Hyperactivity Disorder (ADHD), along with other challenges in the diagnostic process.[1] Social stigma can obstruct clinicians from diagnosing children and caregivers from seeking a diagnosis. Stigma may influence clinicians to think that safeguarding a child from stigma associated with the disorder by not diagnosing the child with FASD will be beneficial for the child's mental health and social adaptation.[25] Similarly, caregivers, including birthmothers, may hide FASD to avoid stigma surrounding PAE.[26] This can be a significant deterrent to FASD diagnosis because the requirement of PAE confirmation is one of the most prominent obstacles to early and correct diagnosis of FASD for affected children who do not possess the distinct facial features of FAS. Moreover, children who are in foster/adoptive care circumstances are especially susceptible to lacking information regarding PAE as a result of the absence of a biological caregiver when an evaluation is being performed.[24] Lack of knowledge surrounding FASD is another factor that delays diagnosis. The lack of knowledge pertaining to FASD is apparent from research findings that a large number of healthcare clinicians do not have sufficient training related to FASD,[28] which likely undermines their ability to identify signs of the disorder within individuals and appropriately diagnose them. Further elevating the importance of pediatric diagnosis, adult neurologists are typically

inexperienced with FASD,[1] which may prevent them from diagnosing and appropriately linking their adult patients to care.

At a population level, effective FASD diagnostic and reporting systems are preconditions for efficient allocation of an array of public health interventions, ranging from those seeking to reduce alcohol consumption during pregnancy, to pediatrician training in FASD diagnosis, to increased funding for effective early intervention programming and family supports. Hindrances to the referral process, insurance issues, and proximity to diagnostic services are among the conditions that lead to underascertainment of children diagnosed with FASD. However, there was limited existing qualitative research that explored barriers to diagnosis of FASD. To add to this problem, no qualitative study examined barriers to evaluation and diagnosis of FASD in the United States. Applying qualitative methods to analyzing barriers to evaluation and diagnosis of FASD is important because data from numerous health settings have illustrated that applying live experiences to decision making pertaining to health services leads to amenable and accessible services and can enhance the quality of care outcomes.[30,31]

This study of the process of the evaluation and subsequent diagnosis of children increased qualitative evidence regarding barriers to timely FASD diagnosis by using semi-structured one-on-one interviews to identify and understand barriers to evaluation and diagnosis of FASD based on lived experiences of caregivers of children suspected of having FASD and clinicians who evaluate and diagnose children with FASD. By recruiting clinicians who work at Emory University in Atlanta, GA and caregivers who reside in the metro Atlanta area and received services from Emory's Neurodevelopment and Exposure Clinic, this study also filled the gap in qualitative studies assessing the barriers to FASD diagnosis in the United States. The findings from this research informs improvements to facilitate early diagnosis and treatment of

FASD, which is the underlying goal of this project, and thus ameliorate the various consequences of FASD that cause individuals living with the disorder to possess a poor quality of life.

Methods

Study Design:

The study team implemented qualitative methods to explore the research question, because these methods excel at exploring participant experiences and interpretations of phenomena (e.g., FASD-related diagnostic barriers).[32] We gathered data via in-depth one-on-one interviews because they permit researchers to explore sociocultural contexts of individuals' lives and they are crucial to establishing rapport.[32] These are essential strengths given the research topic. We did not use focus groups because we believed that clinicians might feel uncomfortable discussing certain barriers to FASD diagnosis and treatment, such as stigmatizing attitudes, during focus groups. Likewise, caregivers may not feel safe relaying details surrounding PAE in a group setting.

Interviews were semi-structured. Interview guides posed open-ended questions, thus opening the floor for participants to describe phenomena that may be unanticipated by us and existing literature. Semi-structured approaches also permit interviewer flexibility, allowing them to pose novel follow-up questions in response to unanticipated or complex participant observations.[33] The newfound insight and descriptive data collected from responses to these open-ended questions can bolster data analysis and the findings.

Eligibility Criteria and Recruitment:

The sample recruited for this study consisted of two groups: (1) clinicians who might be involved in screening, evaluation/diagnosis, or linkage to care for children living with FASD and (2) caregivers of children who may have been diagnosed with FASD.

Clinicians:

In order to be eligible for the study, clinicians were required to:

(1) be at least 18 years old;
(2) be currently employed by Emory University;
(3) have worked in this position at Emory for at least 6 months;
(4) oversee the screening, evaluation, or diagnosis of children suspected of having an FASD or linkage of children suspected of having or diagnosed with FASD to care services;
(5) and be sufficiently fluent in English to complete the screener and consent in that language;
(6) must have treated at least three patients with suspected or diagnosed FASD in the 12 months prior to being screened for the study.

Clinicians were recruited via clinician rosters and peer referral. We created a sampling frame of pediatricians employed by Emory by (1) scanning the website of Emory University's school of medicine for faculty members who were pediatricians; and (2) scanning the roster of physicians and psychologists who had referred patients to Emory Neurodevelopment Exposure Clinic (ENEC) for FASD evaluation. We posited a priori that the volume of patients suspected of having or diagnosed with FASD might be a key source of variation in clinicians' experiences. As

a result, we stratified the clinician sample by the volume of FASD patients that they screened in the past 12 months. High volume clinicians were identified by cross-checking the clinician roster with (1) the ENEC roster of referring clinicians ≥3 people in the past 12 months and (2) review of the remaining members of the roster by two clinician co-authors at ENEC (Claire Coles, PhD and Julie Kable, PhD). All other clinicians were deemed low volume. This classification was confirmed during the clinician screening process via a question on the number of FASD patients the pediatrician reported treating in the past 12 months. Additional stratification that was sought consisted of classifications based on whether clinicians accepted Medicaid or not. However, all clinicians reported that they accepted Medicaid.

Once the stratified roster had been created, clinicians were sampled using simple random sampling. Each clinician in the roster was assigned a number and a random number generator was utilized to select 4 low-volume and 4 high-volume initial potential participants. Research staff then contacted clinicians and screened those who were interested. If potential participants were unreachable after three outreach attempts, or if they screened ineligible, research staff used the random number generator to identify the next clinician. Random Sampling was complemented with snowball sampling, in which enrolled clinicians recommended another clinician to us.

Caregivers

To be eligible to take part in the study as a caregiver, individuals needed to:

(1) be at least 18 years old;

(2) be a biological parent, adoptive parent, foster parent, or other legal guardian of a child (less than 18 years old) who had been diagnosed with FASD and received services at Emory Neurodevelopment Exposure Clinic (ENEC) within the past 5 years;
(3) live in the Atlanta metropolitan area; and
(4) be sufficiently fluent in English to complete the screener and consent in English.

ENEC is a component of the Center for Maternal Substance Abuse and Child Development (MSACD) in the department of psychiatry and behavioral sciences at Emory University's School of Medicine. ENEC provides diagnosis and treatment to children who are between 0 and 21 years old and have a history of prenatal exposure and developmental/behavioral issues.[34]

Caregivers for the study were recruited via two methods: (1) flyers distributed by ENEC clinicians to potentially eligible caregivers; and (2) ENEC recruitment rosters. ENEC developed a census of caregivers of children who had received services at the clinic between 2018 and 2023 and who had consented to be contacted about future research opportunities. These caregivers were sent preliminary recruitment letters that informed them about the study and the impending contact they would receive from research staff. Caregivers who expressed interest in participating in a subsequent contact were screened for study eligibility in the order that they appeared on the census provided by ENEC.

Data Collection

Interview Guide

The semi-structured interview guides for both the clinician and caregiver interviews were developed in collaboration among the co-authors (myself; the thesis committee chair, Hannah Cooper, PhD; staff members of the CDC, and staff members of the Minnesota Department of Health) using existing FASD literature and expertise from several FASD clinicians employed by Emory University as a foundation. The interview guides underwent multiple rounds of review and revision, which all members of this collaboration contributed to. The guide was amended in response to interviews with participants.

Clinicians:

The clinician interview guide was organized into the following domains: screening, evaluation, diagnosis, and linkage to care (see table 1 for definitions). The modular format of this interview guide allowed interviewers to explore only modules that were relevant to each participating clinician and skip others. Each module in the clinician interview guide contained questions related to clinicians' procedures for the designated FASD healthcare process that they are responsible for and their experiences regarding facilitators and barriers for each corresponding FASD healthcare process.

Screening	A process to identify an individual who may have an FASD and might require further testing to receive a formal diagnosis.
Evaluation	Defined by a process to differentiate people who may have FASD from those who do not.

	This might include gathering information on whether the biological parent has a history of PAE, tests for pediatric neurocognitive/behavioral functioning, dysmorphic features such as facial dysmorphia, and growth parameters (prenatal and postnatal).
Diagnosis	Regarded as a clinical decision that a patient does or does not have FASD based on the evaluation.
Linkage to Care	Associated with providing treatment to patients diagnosed with FASD and/or coordinating care with other healthcare clinicians for these patients.

Table 1. Definitions of domains in the clinician interview guide

Caregivers:

The caregiver interview guide explored the following domains: triggers/seeking help, diagnostic journey, diagnostic delays and challenges, information exchange, and services. Triggers/seeking help referred to the factors that prompted caregivers' awareness of the possibility of their child having FASD and their decision to pursue an FASD evaluation for their child. The diagnostic journey represents the steps that caregivers went through and the types of healthcare professionals they interacted with from the time they decided to have their child

evaluated up until the child received a diagnosis and ongoing care for FASD. The diagnostic delays and challenges section queried the challenges and setbacks caregivers may have experienced while pursuing a FASD diagnosis. Information exchange probes about the information a caregiver received from clinicians while seeking an FASD diagnosis for their child, information that caregivers provided clinicians during the diagnostic process, instances of communication gaps that caregivers experienced with clinicians, and how caregivers shared information about their child's FASD diagnosis with various individuals, such as the child's primary care clinician. Services was the final domain, which explored the services, including behavioral interventions and support services, and recommendations that were offered to the caregiver for themself or for their child. Similar to the clinician interview guide, each section possessed questions linked to the experiences that caregivers may have had regarding different elements of the diagnostic process and the facilitators and barriers that these caregivers may have experienced in relation to the aforementioned components of the diagnostic process.

Interview Process

After informed consent was obtained, interviews were conducted via Zoom or in-person, depending on the participant's preference. Interviews lasted up to an hour. However, follow-up interviews were scheduled and done with some clinicians who did not have time during the initial interview to answer questions for all of the domains they were involved with in the FASD care process. Clinicians received a $50 e-gift card and caregivers received a $75 e-gift card for their participation.

Interview audio was recorded and audio recordings were transcribed verbatim using NVivo's audio-transcription service. All transcriptions were checked for accuracy by the study team.

Data Analysis

Braun and Clarke's 6-phase thematic analysis approach was utilized to analyze the interview transcripts. Thematic analysis allows us to pinpoint, analyze, and report salient themes, specifically common barriers to the diagnostic process for FASD, across interviews. These 6 phases are: 1) familiarizing yourself with your data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report.[35]

A single codebook was developed covering both caregiver and clinician transcripts. Specifically, we developed an initial codebook (i.e., codes and their definitions) by applying deductive and inductive methods to clinician interviews and then iteratively editing the codebook as more transcripts were coded (See appendix 3). We then iteratively expanded this codebook (codes and definitions) to encompass phenomena described in caregiver interviews. Necessary amendments to the codebook were discussed among the study team. One of the study team members, Jordan Hill-Rucker, applied the codes to each transcript using NVIVO 14. Memos were developed by project team members, Jordan Hill-Rucker and Dr. Cooper, to search for themes (step 3) and iteratively review, define, and name them (steps 4 & 5).

Data Management

Several data management logs were made to keep track of the study's progress and related information. A recruitment/enrollment log was created in Microsoft Excel for both caregiver and clinician participants to monitor when they were contacted for recruitment and how many times they were contacted for recruitment. This helped us ensure that we did not reach out to a potential participant to recruit them more than 3 times. We also documented participants' names, positions (only applied to clinicians), contact information, their progress within the study, and their participant ID. To maintain data confidentiality, caregiver participants' IDs were paired with the initials of their first and last names instead of their full names.

A data analysis log that observed the progress that the study team made with checking transcriptions, analyzing transcriptions, and saving and deleting audio recordings of interviews was also developed. It is important to note that the audio from one of the caregiver interviews, C014, was corrupted, therefore the majority of the data from this interview was lost. In spite of this, we believe we have achieved data saturation with the other caregiver interviews. Moreover, an incentive log of the Amazon e-gift card codes, which participants they were sent to, when they were sent to each participant, the amount of money associated with each e-gift card, and which study team member distributed the e-gift card was kept to surveil distribution of the incentives. All data management logs were kept on the study's R-drive so that all members of the study team had access to it and were updated accordingly after each study procedure was carried out.

IRB Approval:

Study protocols received IRB approval from the university hosting the project, Emory University. Informed consent (oral) was obtained from individuals who were eligible and interested in participating in the project.

Results

Introduction:

A total of 25 participants were enrolled in this study. Fourteen interviews were conducted with 15 caregivers; one married couple opted to be interviewed together and 11 clinicians were interviewed for this study. Demographics of caregivers, the children of these caregivers, and clinicians that were required to determine study eligibility and/or hypothesized to be pertinent to the study's findings were collected during the screening process. The number and percentages of individuals that fit each demographic were calculated.

Caregiver Demographics

Almost all caregivers identified as women (93%) and non-Hispanic White (93%). Almost half of the caregivers (47%) were between the ages of 30 and 49 years old. Furthermore, almost all of the caregivers were adoptive parents (93%). (See table 2)

Table 2. Caregiver Demographics

Caregiver Demographic	% (N)

Gender	
Man	7% (1)
Woman	93% (14)
Transgender/other	0% (0)
Race/Ethnicity	
Non-Hispanic White	93% (14)
Hispanic/Latinx, any race	0% (0)
Black/African-American	7% (1)
Age	
30-49 Years Old	47% (7)
50-59 Years Old	33% (5)
+60 Years Old	20% (3)
Relationship to Child	
Adoptive Parent	93% (14)
Foster Parent	0% (0)
Other	7% (1)

Children of Caregiver Demographics

Half of the children of the caregivers who participated in this study were between the ages of five and 12 years old (50%). Half of the children were diagnosed with FASD when they were less than five years old (50%) while the other half were between the ages of five and 12

years old. In terms of insurance coverage, the majority of the children were covered by Medicaid (86%). (See table 3)

Table 3. Demographics of Children of Caregivers

Children of Caregiver Demographics	% (N)
Current Age of Child	
Less Than 5 Years Old	29% (4)
5-12 Years Old	50% (7)
13-17 Years Old	21% (3)
Age at time of FASD Diagnosis	
Less Than 5 Years Old	50% (7)
5-12 Years Old	50% (7)
13-17 Years Old	0% (0)
Child's Insurance	
Medicaid	86% (12)
Private	7% (1)
Medicaid & Private	7% (1)
Other	0% (0)

Clinician Demographics

Almost all the clinicians identified as women (91%) and most of the clinicians identified as non-Hispanic White (64%). Nearly half of the clinicians reported that they were between 30 and 54 years old (45.5%) and nearly half of the clinicians reported that they were between the ages of 55 and 79 years old (45.5%). Nearly half of the clinicians in this sample were psychologists (46%) and nearly half of the clinicians practiced in their profession for at least 30 years (45.5%). Furthermore, almost half of the clinicians who participated in this study saw 11-99 patients suspected of having FASD in the 12 months prior to being screened for this study (45.5%). (See table 4).

Table 4. Clinician Demographics

Clinician Demographics	% (N)
Gender	
Man	9% (1)
Woman	91% (10)
Race/Ethnicity	
Non-Hispanic White	64% (7)
Hispanic/Latino	27% (3)
Asian	9% (1)
Age	
30-54	45.5% (5)
55-79	45.5% (5)
80+	9% (1)
Position	
Psychologist	46% (5)
Psychiatrist	18% (2)
Consultant	9% (1)
Education Specialist	9% (1)
Neurologist	9% (1)

Pediatrician	9% (1)
Years Practicing in Profession	
1-9	27.3% (3)
11-19	9% (1)
20-29	18.2% (2)
+30	45.5% (5)
Amount of FASD Patients Seen in Past 12 Months	
1-10	36.4% (4)
11-99	45.5% (5)
100+	18.1% (2)

Key Findings

A number of prominent barriers to the evaluation and diagnosis processes were reported by clinicians and caregivers, but 3 key barriers were most prevalent.

Barriers to Evaluation/Diagnosis: Documented Confirmation of PAE as Diagnostic Criteria

Documented confirmation of PAE for the child being evaluated for FASD is a key diagnostic criterion for FASD. Participants reported that one of the following criteria must be

met to be considered suitable documentation of PAE: (1) the child's biological mother must directly tell the clinician(s) who are evaluating the child that they consumed alcohol while they were pregnant with their child; (2) written acknowledgement of the mother's alcohol consumption during pregnancy from one of the biological parents; (3) medical/birth records or social service/legal records of the biological mother's alcohol consumption during pregnancy, or (4) eye witness reports of the mother's alcohol consumption during pregnancy. However, clinicians lacking reliable confirmation of PAE can be the principal obstacle for a child being diagnosed with FASD despite the child meeting other diagnostic criteria. Only a child's possession of alcohol-related dysmorphia enables a clinician to forgo the need for PAE confirmation to make an FASD diagnosis.

Clinician E4 outlined some of the aforementioned criteria for suitable documentation of PAE:

You can't say "someone told me"...[the report] can't be secondhand. It's something someone had to observe. We sometimes ask for someone to write down if they observed it so we have clear documentation. …if we don't have clear documentation and don't have a reliable reporter, we require that there be alcohol related dysmorphia to make a diagnosis…

There are various factors that inhibit confirmation of PAE for evaluation and diagnosis of FASD. Multiple participants communicated that records related to biological mothers' alcohol consumption tend to be difficult to obtain or the records simply do not exist. Stigma towards consumption of alcohol during pregnancy and a biological mother's involvement in a DFCS case (Division of Family and Children Services) were notable conditions stated to discourage

biological mothers from acknowledging that they consumed alcohol while they were pregnant. Clinicians disclosed that falsifications on the part of non-biological caregivers of the child being evaluated for FASD were significant obstacles to confirmation of PAE as well. Several clinicians reported that caregivers, including those who are family members of the biological mother, may be unable to provide accurate information about the biological mother's alcohol consumption if they did not directly observe the consumption. These caregivers may also be unable to relay accurate information if a parallel event related to the biological mother's alcohol consumption that can potentially influence caregivers' attitudes, such as a custody battle, is taking place. As a result, statements from non-biological caregivers about a child's PAE can be unreliable and not suffice as confirmation.

Clinician E4 expressed how falsifications from non-biological parents regarding the biological mother's consumption of alcohol can make their statements about PAE unreliable:

every so often, we get a foster care parent who is accentuating problem behaviors…and talking about rumor mills of exposure and we won't...take that as [a] valid report.

The difficulty of obtaining documented confirmation of PAE was more often described as a barrier to evaluation and diagnosis by clinicians than caregivers, particularly as a barrier to clinician's receipt of diagnostic information. Multiple caregivers expressed frustration with the utilization of PAE confirmation as diagnostic criteria for FASD and believed that it unnecessarily prevents children who they believe clearly have FASD due to their possession of other diagnostic criteria from receiving a needed FASD diagnosis.

In the interview with caregivers C5 & C9, C5 discusses how confirmation of PAE prevented one of her children from being diagnosed, but was not a barrier for a different child's diagnosis:

"…there were two girls…that we also took to [name of clinic]. Neither one of them qualified for the official [FASD] diagnosis. They said…our oldest daughter would have if there was proof that mom drank. …she checked all the boxes except that one. Mom wouldn't admit it. …the first brother like, was so severe, they didn't need that proof… The second daughter…she's got some things going on, but she didn't check really enough boxes for anything"

Barriers to Evaluation/Diagnosis: Affordability of evaluations

In order for a child to be diagnosed with FASD, clinicians must perform evaluations to assess whether the child meets the diagnostic criteria for this disorder through their history along with physical, neurological, psychological, and cognitive characteristics. Clinicians and caregivers reported that affordability of evaluations, specifically lack of insurance coverage for and prices of evaluations, can hinder the process of caregivers getting their children evaluated for and in turn, diagnosed with FASD. Insurance served as a barrier in two ways: either the insurance plan did not provide any or sufficient coverage for evaluations or clinicians did not accept it. In particular, having Medicaid posed this obstacle for caregivers who sought evaluations for their child suspected of having FASD because it was not accepted by clinicians or it offered limited coverage. For children whose Medicaid would not cover evaluations or simply limited coverage of the costs, out of pocket costs were too expensive for caregivers to

afford. Several caregivers specifically mentioned that it is challenging to find psychiatrists who would accept Medicaid to evaluate a child.

"the [psychologists]…nobody wants to take Amerigroup, so…you just get kicked around from place to place and it's just so unfair because what are you going to do? You're gonna pay $2,000, $1,800…that was the price that I was quoted for…having…an assessment done"

Clinician E1, stated that funding received by ENEC from Georgia state legislature enables them to evaluate children suspected of having FASD despite the high price of evaluations and the lack of Medicaid coverage for these evaluations. However, ENEC's limited funding restricts the number of children that the clinic could evaluate:

...Um, we are able to see people and do a comprehensive evaluation of them because we are funded by the state legislature to specifically see children on Medicaid who could not afford to be seen by us otherwise because it costs about $2,000 for an evaluation and Medicaid will pay $148, so if we weren't being funded by the state legislature specifically to deal with this, these children could not be seen. So, there needs to be a-and we receive only a little bit of money. I mean, it's not enough to see everybody who needs to be seen, so I'd say the biggest barrier to this kind of thing for children is the insurance companies.

Furthermore, if the caregivers can not afford to get their child evaluated for FASD, it is difficult for clinicians to obtain information that is acquired through evaluation assessments and is required to diagnose a child with the disorder, such as information regarding a child's growth

deficits, facial dysmorphia, and psychological issues. This relates to both various standard assessments that are typically conducted at one clinic and supplementary assessments that are done at different sites. One of these supplementary evaluation assessments that appear to be typically conducted at separate sites from other standard assessments are genetic tests. Genetic tests are a form of evaluation that clinicians suggest caregivers pursue to help the clinicians rule out whether a genetic issue is causing the child's symptoms instead of FASD and is a prominent evaluation that Medicaid often does not want to pay for children to get is a genetic test. Without insurance coverage, these tests can be unaffordable.

Clinician, E4, mentioned how the expensive cost of genetic tests and lack of Medicaid coverage for these tests can pose as a barrier for diagnosis of FASD:

Occasionally, there are situations where…we need additional outside information, so we will sometimes need to have a genetic testing done to rule out another genetic syndrome before we can do the diagnosis. …but then we have a lot of...problems with insurance that doesn't wanna fund those assessments and so oftentimes we're left in this zone of ambiguousness where we can't rule out a certain thing because it wouldn't let us do some sort of genetic testing and because they're on Medicaid usually [laughs] and that limits what they'll consent to do and it's often a dilemma for families. So we've done various work arounds trying to get it at a lower cost for families. There are certain commercial labs that...they try your insurance and then when they can't get it, they'll do it for $100, but for some families, you know, they don't even have the $100, so that can be a limitation.

Barriers to Evaluation/Diagnosis: Long Wait Time for Evaluation Appointments

Long wait times for caregivers and their children was a prevalent barrier to evaluation and diagnosis of FASD communicated by both clinicians and caregivers. As previously mentioned, evaluations must be done to discern whether a child meets the diagnostic criteria for FASD. Unfortunately, there are long wait times for each of these appointments. Clinicians and caregivers expressed wait times ranging from six weeks to 2 years for specific evaluations.

"…such a long wait to get an appointment. …we had another one of the children who it took over a year to get an appointment in there, but…it was because we had been trying to get an appointment and we couldn't. ...it was just that...they're backed up".

Various factors were attributed to the long wait times that caregivers and their children experience. Several caregivers mentioned that they had to wait a long time due to constraints on their availability to attend appointments posed by health concerns of their other children. One of these caregivers was C02:

"We had to reschedule one of the evaluation appointments because another kid was in the hospital. ...So like, what are you gonna do? ...it took a long time, like it took longer than I wanted, but there weren't really any reasons other than that one hospitalization for it to take so long. ...It was probably like six weeks."

According to one of the clinicians, E1, lack of staff availability at ENEC was driven by the lack of funding that the clinic receives. General lack of clinics and clinicians that evaluate or

diagnose FASD in the city of the caregiver and their child was chalked up to lack of education about FASD and training for evaluating and diagnosing this disorder.

Long wait times to attend evaluation appointments were more frequently discussed by caregivers than by clinicians as a barrier to the evaluation and diagnosis process of FASD, likely because it is a heavier burden for them and their children than clinicians.

Caregiver, C016, described the importance of getting a child diagnosed early in order to receive effective services. This participant linked this urgency among caregivers along with the general lack of clinicians that evaluate children with FASD to the long wait to attend an appointment at ENEC:

there was just concern that…if this is going on, we need to have it diagnosed because there were...milestones that weren't being met and...if we get this diagnosed early, the better the chances of us being able to work with it through the school system and, like, just getting resources in place that are needed. So if you don't have a diagnosis, you can't go anywhere. You can't go forward because…you need to have a diagnosis...I guess, that's why it's so difficult to get a child seen in that clinic because…there's just not a lot of...folks who diagnose...

Other Findings

Multiple other barriers to evaluation and diagnosis of FASD were identified by clinicians and caregivers. These barriers included lack of awareness and education about FASD among clinicians and difficulty of obtaining information necessary for assessing whether children meet diagnostic criteria for FASD from children's medical records.

Summary of Findings

Numerous circumstances serve as barriers to evaluation and diagnosis of children suspected of having FASD. These obstacles range from PAE confirmation to affordability of evaluations to logistical challenges experienced by caregivers.

Discussion

Primary clinical contact with FASD typically happens during childhood, which is a fruitful period for identification, diagnosis, and treatment of the disorder. Such early intervention may mitigate negative outcomes of FASD such as harmful effects on neurodevelopment, secondary disabilities, including learning disabilities and increased risk of substance use; lifelong physical and cognitive disability, behavioral disturbance, comorbid psychiatric and medical conditions, unemployment, homelessness, and imprisonment. However, existing research has shown that FASD is strikingly underdiagnosed in most clinical settings despite occurring as often as autism spectrum disorder. There is notable variability of prevalence estimates as well, which may be attributed to diagnostic challenges. This study aimed to identify the barriers to evaluation and diagnosis of FASD that lead to underascertainment of the disorder.

This was carried out by performing one-on-one in-depth, semi-structured qualitative interviews with clinicians employed by Emory University who screen, evaluate, or diagnose children suspected of having FASD or treat children diagnosed with FASD along with caregivers of children who were diagnosed with FASD and received services at ENEC. Semi-structured qualitative interviews enabled us to acquire insider insight about barriers to evaluation and

diagnosis of FASD from key informants who have experience with the diagnostic process for children suspected of having FASD and care-coordination for children diagnosed with an FASD. We hypothesized that the findings from these interviews could inform intervention strategies for averting obstacles to FASD diagnosis and care coordination and as a result, assist in the mitigation of harmful outcomes and lifelong symptoms of the disorder among children and improve their quality of life as they age.

Data gathered from the in-depth semi-structured interviews with the 11 clinicians and 15 caregivers revealed that documented confirmation of PAE as diagnostic criteria, affordability of evaluations, and long wait times for evaluation appointments were key barriers to evaluation and diagnosis of FASD. Similar to reports in existing literature, the necessity of PAE confirmation was shown to be one of the most significant hindrances to diagnosis of FASD for children who do not display facial dysmorphia and it was particularly difficult to obtain information related to PAE for children in custody of foster and adoptive parents because their biological caregivers typically were not present when the FASD evaluation is being conducted.[24] We also found that PAE confirmation is a barrier to evaluation and diagnosis of FASD because biological parents do not want to acknowledge that the biological mother used alcohol while pregnant with the child, healthcare providers who see the child before the clinicians who evaluated or diagnose the child with FASD tend not to ask about PAE appropriately or ask at all, according to clinicians, foster and adoptive parents are not informed about their child's exposure to alcohol due to biological parents' reluctance to acknowledge the biological mother's alcohol consumption or this information getting lost in the foster care system as the children are switched to someone else's custody or switch healthcare providers.

Also in alignment with past research, we found that stigma could inhibit caregivers from seeking a FASD diagnosis for their children.[26] This was demonstrated by reports that stigma towards alcohol consumption during pregnancy discourages biological mothers from disclosing their use of alcohol while they were pregnant with their child, who is currently in the custody of a parent other than the biological parent, because they fear being scrutinized and facing legal consequences for their past actions. Lack of awareness around FASD among clinicians was a barrier to evaluation and diagnosis communicated by both caregivers and clinicians, as has been observed in previous research as well.[31] This correspondence likely exists because lack of awareness regarding FASD among clinicians inhibits them from recognizing the signs of FASD, especially when discerning comparable symptoms of FASD from other medical conditions, and in turn, referring a child who may have the disorder for FASD evaluation or diagnosing the child with FASD. Furthermore, the difficulty of obtaining children's medical history from their medical records was identified as a barrier to FASD evaluation and diagnosis in existing literature.[39,40] This finding may align between this study and past research because of a lack of consistent and satisfactory data collection and documentation by clinicians during patient visits, recordkeeping, and the exchange of clinical information in healthcare systems across geographic regions.

On the other hand, affordability of evaluations was not identified as a barrier in other qualitative research, which may be due to insurance coverage constraints in the United States. Other qualitative studies that examined barriers to FASD evaluation and diagnosis were done outside the U.S. in countries such as New Zealand and Australia,[36-38] which both have universal healthcare, so healthcare policies that influence the prices of FASD evaluations may differ. Long wait times were not identified in existing literature either, which may be due to contrasting

practices and expectations of healthcare systems in the other countries where similar studies were done

Strengths

The main strength of this study is that it adds to the limited qualitative evidence of barriers to the diagnostic process of FASD around the world and particularly produces qualitative evidence of barriers to the diagnostic process of FASD in the United States, which was previously nonexistent.

Limitations

There are multiple limitations to the findings from this study. Clinicians were only recruited from Emory University due to funding constraints. Since all the clinicians from this samplework at Emory University, the barriers to evaluation and diagnosis of FASD that were reported by these clinicians may not be found in other healthcare systems or experienced by clinicians that work at these institutions. Along with this, the clinician sample possesses a lack of diversity regarding the clinician's positions. Considering that 64% of this sample was either a psychologist or psychiatrist, this study may not adequately represent barriers to evaluation and diagnosis of FASD that are experienced by other clinicians involved in these processes, particularly pediatricians. Future qualitative research should focus on recruiting a sample of clinicians who hold work in various disciplines related to evaluating and diagnosing individuals with FASD to determine if the findings from this study may be unique to clinicians who hold particular positions.

The external validity of the findings from the caregiver sample may be limited due to the lack of diversity among the participants. The findings may apply to adoptive parents, but not biological or foster parents. Moving forward, recruitment of biological caregivers should be prioritized by qualitative researchers analyzing barriers to FASD evaluation and diagnosis to gather insight into their experiences. Although we acquired information regarding foster parents' experiences with barriers to the evaluation and diagnostic process of FASD for their foster children, this data came from caregivers who are now adoptive parents. Barriers to evaluation and diagnosis that foster parents deal with may have changed since these caregivers adopted their children. Additionally, the majority of the caregiver sample were non-Hispanic White individuals, which may limit the findings from this sample from extending to caregivers of other races or ethnicities. Only one non-White individual was enrolled in the study, who was a non-Hispanic Black individual. Future qualitative research should emphasize exploration of the barriers that non-White caregivers face when pursuing an FASD evaluation and diagnosis for their children. Results from these analyses could potentially inform us about whether particular barriers to FASD evaluation and diagnosis specifically impact caregivers of certain races or ethnicities and what social factors influence these barriers.

Other limitations to the findings of the caregiver sample include the lack of caregivers whose children were covered by private insurance in this study. This may limit the findings pertaining to the caregiver sample to caregivers who have Medicaid. Only two caregivers in the study reported that their child had private insurance (C012 & C017), so we did not receive much information about caregivers' potential experiences with barriers posed by private insurance when getting their child evaluated for FASD. Future qualitative studies should emphasize evaluating experiences of barriers to evaluation and diagnosis of FASD for caregivers of children

covered by private medical insurance to discern if private medical insurance may avert barriers to evaluation and diagnosis of FASD and pose as a facilitator. It is also important to keep in mind that we may not have identified barriers to FASD evaluation and diagnosis that are relevant to individuals over 18 years old and their caregivers because caregivers of individuals with FASD who were over 18 years old were excluded from the study. Qualitative researchers in the U.S. who aim to further explore barriers to FASD evaluation and diagnosis may want to consider collecting data specifically from individuals diagnosed with FASD who are over 18 years old and/or their caregivers. Data collected from these populations can increase knowledge about barriers to FASD evaluation and diagnosis that specifically impact adults whose FASD symptoms were not recognized during childhood or were misdiagnosed as children. Moreover, the inclusion of caregivers of children who received services at ENEC within the past 5 years may limit the external validity of some of the findings from the caregiver sample in view of the fact that evaluation and diagnostic processes and barriers may have changed in between the time some of the caregivers received services for their children at ENEC. This inclusion criteria also subjects these results to recall bias. Some caregivers even disclosed that they did not remember certain details about their experience with their child's FASD diagnosis. In future research, data should be gathered from participants sooner after they receive diagnostic services.

Public Health Implications

A range of strategies should be implemented to mitigate the impact of the discussed barriers to evaluation and diagnosis of FASD. Stigma related to biological mothers' alcohol use during pregnancy needs to be reduced, particularly by way of education and training among clinicians, to help caregivers feel comfortable and safe enough to discuss their alcohol use with

healthcare providers and enable these providers to effectively obtain satisfactory documented PAE confirmation. On top of that, healthcare providers should be trained to appropriately ask caregivers, especially biological caregivers, about the biological mothers' alcohol use during pregnancy in a manner that does not stigmatize alcohol use during pregnancy and discourage caregivers from disclosing it. Facilitating acquisition of this information, which can be crucial for diagnosing a child with FASD, will aid FASD diagnosis, and in turn, help children get needed care for FASD.

Expanding insurance coverage, particularly Medicaid expansion in states like Georgia, would likely make FASD evaluations more affordable. Financial support from states are also needed to reduce the cost of evaluations. Understanding the rationale underlying the lack of Medicaid coverage for the costs of genetic tests and other evaluations for children suspected of having FASD may inform methods of reforming Medicaid coverage of evaluations and help remove affordability as a barrier to these services that are required for FASD diagnosis. For example, if insurance companies are deeming FASD evaluations as unnecessary services, perhaps increasing awareness about FASD in the healthcare system may lead to insurance companies deciding to cover these assessments. It may be useful to know if caregivers are making appeals to insurance companies that do not want to cover FASD evaluations as well, and if so, what are the outcomes of these appeals. If appeals can successfully facilitate insurance coverage of evaluations for FASD, caregivers can be recommended to increase their chances of affording to get their child evaluated for FASD in a timely manner by making appeals to insurance companies. Furthermore, learning about how private insurance compares to Medicaid in regard to covering the costs of evaluations for FASD can reveal if it may be more beneficial

for caregivers to have private insurance instead of Medicaid when getting their children evaluated for FASD.

Encouraging and incentivizing clinicians to obtain training related to FASD evaluation and diagnosis and provide evaluations would likely increase the accessibility of clinics and clinicians that offer evaluation services and as a result, aid the reduction of wait times for evaluation appointments. An increase in funding to clinicians and clinics who currently perform FASD evaluations could allow these clinicians to expand their resources, increase their availability to conduct FASD evaluations, and therefore cut down on wait times for evaluation appointments.

Conclusion

This study revealed that there are a multitude of barriers that hinder timely, accurate, and successful diagnosis of FASD for children suspected of having the disorder. Practices and policies associated with the healthcare system need to be reformed to nullify these barriers. Although some barriers are more detrimental to the diagnostic process of FASD than others and easier to resolve than others, they all prevent children suspected of having FASD from getting a diagnosis that is necessary for them to receive timely treatment and support services to address their health needs and improve their quality of life. As a result, despite caregivers being subjected to burdens to their positions as caregivers and clinicians being subjected to challenges to their jobs by barriers to evaluation and diagnosis of children suspected of having FASD, these children suffer the heaviest burden from these barriers to evaluation and diagnosis of the disorder.

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Appendices

Appendix 1: Clinician Interview Guide

EMORY INTERVIEW GUIDE WITH CLINICIANS

BACKGROUND INFORMATION

Before we start with the more detailed questions, I would like to ask a few orienting questions.

1.. Warm Up 1: What do you look forward to most when you start your workday?

2. Warm up 2: Why did you choose this career?

3. Can you tell me whether you ***screen***, ***evaluate***, ***diagnose and/or link to care*** children suspected of having an FASD? For the purposes of this interview,
    i. ***Screening*** refers to a process to identify an individual who ***may*** have an FASD, and might require further testing to receive a formal diagnosis.
    ii. An ***evaluation*** for an FASD is designed to differentiate people who have FASD from people who do not. It might include gathering information about whether the birth parent has a history of prenatal alcohol exposure; tests for pediatric neurocognitive/behavioral functioning, dysmorphic features (particularly, facial dysmorphia), and growth parameters (prenatal and postnatal).
    iii. We are defining ***diagnosis*** as a clinical decision that a patient does or does not have FASD, derived from the evaluation.

If a participant is involved with Screening, go to the Screening Module on Page 2.

If a person is involved with evaluation but not screening, go to the Evaluation Module on page 3.

If the participant is involved in diagnosis but not evaluation or screening, proceed to the Diagnostic Module on page 4.

If the participant is only involved in linkage to care/provides care, proceed to the Linkage to Care module on page 6.

II. SCREENING MODULE

1. Can you walk me through the process of screening a child for an FASD?
    a. What does this entail?
    b. Are there any characteristics or issues that prompt a screening?
    c. What do you do when there is uncertainty about the need for screening?

2. How do you typically obtain information about prenatal alcohol exposure?

3. In your experience, how do cultural and/or social perceptions regarding alcohol use during pregnancy influence the screening process?
    a. Do you ever have concerns about the accuracy of caregiver responses? Please describe.
        i. What do you do when you have concerns?
    b. What do you do if there is missing or potentially inaccurate information about potential prenatal alcohol exposure (for example, if the caregiver is not the birthing parent)?

4. How do you document information in the patient record (e.g., specific field, notes, etc.)?

5. What is the **referral process for an FASD evaluation**?
        i. If you provide referrals outside of Emory, what does that look like?
        ii. What is the role of your nursing team in making these referrals?

6. What challenges or delays may be experienced by ***providers*** during the referral process for an FASD evaluations?
        iii. Probes: What factors contribute to these delays and challenges? EHR system? Insurance? Provider availability? Caregiver response?

7. What challenges or delays may be experienced by ***patients*** during the referral process for evaluations?
    a. Probes: What factors contribute to these delays and challenges? EHR system? Insurance? Provider availability? Caregiver response?

8. What facilitates successful referrals for the evaluations?
    a. Probes: EHR system? Insurance? Provider availability? Caregiver response?

9. What **information do you share** with other providers/specialists who will be conducting the evaluation about the patient?
    a. How do you share this information?
    b. What barriers exist to sharing this information?
    c. What facilitates this sharing?

If a person is involved with <u>evaluation</u>, go to the Evaluation Module on page 3.

If the participant is involved in <u>diagnosis but not evaluation</u>, proceed to the Diagnostic Module on page 4.

If the participant is only involved in <u>linkage to care</u>, proceed to the Linkage to Care module on page 6.

If the participant is not involved in evaluation, diagnosis, or linkage to care, go to Final Insights Module, on page 7.

III. EVALUATION MODULE

*[**If just completed the Screening Module, say:*** I want to turn now to the Evaluation Process. As a reminder, when I use the word "evaluation" I mean a process that is designed to differentiate people who have FASD from people who do not. It might include gathering information about whether the birth parent has a history of prenatal alcohol exposure; tests for pediatric neurocognitive/behavioral functioning, dysmorphic features, and growth parameters (prenatal and postnatal).]

1. What information do you receive about the patient from the referring provider?
    a. How do you receive it?
    b. What facilitates getting this information?
    c. What impedes getting this information?

2. Upon receiving a referral, how do you determine if an evaluation is indeed appropriate?
        i. Are there times you are uncertain? Why? What do you do?

3. When you **interact with caregivers** while evaluating their child for an FASD, how might cultural and social perceptions of alcohol use during pregnancy impact their willingness to have their child evaluated?

4. How have social norms affected responses to questions about prenatal alcohol use?
    a. Do you ever have concerns about the accuracy of caregiver responses? Please describe.
    d. *Probe*: What do you do when you have concerns?
    b. What do you do if there is missing or potentially inaccurate information about potential prenatal alcohol exposure (for example, the caregiver is not the birthing parent)?

5. Please share any specific **barriers or delays** that you have experienced while conducting FASD **evaluations** and the. What factors that contributed to them.?
    a. What about barriers related to getting patients scheduled for an evaluation (e.g., patient prioritization, competing priorities of other types of evaluations, scheduling, etc.)
    b. What has helped overcome these barriers? or what else might help improve FASD evaluations?

6. Who do you work with when performing FASD evaluations?
    a. Probes: Nurse? Genetic counselor? Psychologist? Psychiatrist? Social worker?
    b. Does this person work at Emory University?

7. *If a different person than the provider will be making the diagnosis:* What information do you share to the provider who will be making the diagnosis?
    a. How do you share it?
    b. What facilitates sharing it?
    c. What impedes that process?

If the participant is involved in diagnosis, proceed to the Diagnostic Module on page 4.

If the participant is only involved in linkage to care, proceed to the Linkage to Care module on page 6.If the participant is not involved in evaluation, diagnosis, or linkage to care, go to Final Insights Module, on page 7.

IV. DIAGNOSTIC MODULE

[If just completed the Screening and/or Evaluation Module, say: I want to turn now to the diagnostic process. As a reminder, when I use the term "diagnosis" I mean the clinical decision that a patient does or does not have FASD, derived from the evaluation.]

1. What are all the required pieces of information you need to make an FASD diagnosis?

    a. Are there any challenges you typically experience in collecting the information you need?

        i. *Probe*: Do you have trouble obtaining information from families, other providers, other health or social services systems, education system about FASD, etc.

        ii. What information do you receive about the patient from the provider who conducted the evaluation?

            1. How do you receive it?
            2. What facilitates getting this information?
            3. What impedes it?

2. Once a patient is diagnosed with an FASD, what **diagnostic code** or codes do you use? Please provide the specific codes.
    a. Under what conditions might you select one code or another?
    b. Can you describe any limitations you've encountered related to the availability of relevant diagnostic codes in your EHR system?
        i. How do you handle these limitations?
        j. Is FAS on the list of codes?
        k. What symptoms are on the problem list? Could you describe how an FASD diagnosis is represented in the active problems list within the medical record?
        l. Is the documentation of the diagnosis in the problems list or medical history easily recognizable as FASD or is it non-specific or vague? If it's non-specific or vague, what are some examples of how it is represented~~?~~

3. When might you hesitate to enter the diagnosis into an electronic medical record?
    a. If you do not put it in the EMR, where might you put it instead?

4. When a diagnosis of FASD is provided, how do you share this information with the family?
    a. What do you tell them?
    b. How do caregivers typically respond to this information?

5. When a child is older, how do you share the information with the child themselves?
    a. What do you tell them?
    b. How do they usually respond to this information?

6. Who do you work with when conducting FASD diagnoses?

a. Probes: Nurse? Genetic counselor? Psychologist? Psychiatrist? Social worker?
b. Does this person work at Emory University?

7. *If a different person than the diagnosing provider will be making linking the patient to care:*
   What information do you share with the provider who will be linking the patient to care?
   a. How do you share it?
   b. What facilitates sharing it?
   c. What impedes that process?

If the participant is involved in <u>linkage to care</u>, proceed to the Linkage to Care module on page 6.

If the participant is <u>not involved in linkage to care</u>, go to Final Insights Module, on page 7.

V. LINKAGE TO CARE MODULE

[If the participant has responded to items in a prior module, say: Next, I'd like to ask some questions related to care coordination for children diagnosed with FASD.]

1. When a child is **diagnosed** with an FASD, what **treatment(s)** do you connect them to? By treatment, we mean pharmacological treatments, behavioral interventions, evidence-based therapies, etc.

    a. What helps caregivers successfully connect to these services?
    b. What impedes these connections?

2. When a child is **diagnosed** with an FASD, what **support services** do you connect them to? By services, we mean support groups, personal care assistants or independent living specialists, educational services, social services, etc.

    b. What helps caregivers successfully connect to these services?
    c. What impedes these connections?

3. Please describe your approach to **coordination and continuity of care of the treatment and services you listed** for patients diagnosed with an FASD.

    a. *When working with clinicians who diagnose but are not primary care providers:* How do you coordinate care with the patient's primary care provider?
    b. What helps facilitate coordination and continuity of care?
        i. Probes: EHR system? Insurance? Provider availability? Caregiver response? Family/patient navigator? Family support services (i.e., respite care)
    c. What impedes coordination and continuity of care?
        i. Probes: EHR system? Insurance? Provider availability? Caregiver response? Family/patient navigator? Family support services (i.e., respite care)

Go to the Final Insights Module, on page 7.

VI. FINAL INSIGHTS

Finally, I have just a couple more "bigger picture" questions to get your perspective on how the FASD screening, evaluation, diagnosis, and linkage to care processes can be improved.

1. Overall, **what suggestions do you have** to improve the clinical pathways related to FASD screening, evaluation, diagnosis, and care?
    a. What suggestions do you have to improve access to and quality of clinical information needed for these pathways?

2. There may be multiple providers involved in the process of FASD diagnoses, including providers who screen, providers who evaluate, and providers who diagnose. Overall, **what suggestions do you have** to improve the exchange of clinical information among these providers that is needed to make an FASD diagnosis?

3. Reflecting on your patients' journeys through the process of FASD screening through diagnosis and linkage to care, how do the facilitators you noted **impact patient outcomes**?
    a. How do the barriers impact patient outcomes?

4. Is there anyone on your nursing team that you could refer the study to?
    a. Can I email you later to receive their name?
    b. Can I email you later to receive their contact information?

5. Can you connect us to someone within the Emory system who performs evaluations and/or diagnoses for children suspected of having an FASD?
    a. What is their name?
    b. Can I email you later to receive their contact information?

6. Before we close, is there anything else you'd like to add?

Thank you for sharing your experiences and insights related to your patients' FASD screening, evaluation, diagnosis, and care journey!

Appendix 2: Caregiver Interview Guide

Parent/Caregiver Interview Guide:

1. Triggers/Seeking Help

Structuring Statement: Let's begin by discussing the journey that led you to seek an FASD evaluation for your child, focusing on the circumstances that prompted your awareness and decision to pursue an evaluation.

   a. Could you please tell me about how you first became aware of the possibility of your child having FASD?
      i. Probes
         1. What were the initial concerns or triggers that led you to suspect that your child might have FASD?
         2. How did your primary provider's level of awareness of FASD affect this process?
   b. How did you seek or obtain information about FASD?
      i. Probes
         1. Were there any challenges in accessing relevant or reliable information?
   c. What factors contributed to your decision to pursue a diagnosis?
      i. Probes
         1. Was this process initiated by a provider, or did you proactively seek professional help?
         2. *If caregiver initiated:* How did you decide which professionals or resources to seek help from?
         3. *If provider initiated*: What did they recommend?

2. Diagnostic Journey

Structuring Statement: Now I'd like to shift our focus to your journey through the diagnostic process once you decided to seek an FASD evaluation.

   a. Could you walk us through the steps you went through and the various encounters you had with professionals from the time you decided to have your child evaluated until you finally received a diagnosis?
      i. Probes:
         1. Can you share the sequence and timeline of encounters during this process?
         2. How long did it take from the first suspicion to the actual diagnosis?
         3. What types of professionals did you encounter during this journey and what roles did they play in the diagnostic process?
   b. Do you have any insights or suggestions that you think could improve the process for families?

3. Diagnostic Delays and Challenges

Structuring Statement: As we move forward, I'd like to explore another important aspect of your experience; the challenges and setbacks you encountered during the diagnostic journey.

   a. Can you please describe any difficulties and/or delays you faced in obtaining a referral or diagnosis and the factors that contributed to them?

i. Probes:
1. How have these impacted your child's or your family's well-being and outcomes?
2. Were there any specific barriers encountered in accessing healthcare services or specialists?

b. Based on your experiences, what potential strategies do you think could help overcome the identified barriers or delays?
i. Probes:
1. Are there any resources or services you think could be improved or made more accessible to families seeking a diagnosis?

4. Information Exchange

Structuring Statement: Next, I'd like to shift our focus to talk about the dynamics of information exchange before, during and after your child's diagnosis. I'd like us to explore the details of the information you received, the information requested from you, any instances of communication gaps and how you shared information about your child's diagnosis.

a. Can you start by describing the types of information you received from your healthcare providers throughout this process?
i. Probes
1. Were you offered information about:
- Accessing support services for parents/caregivers
- Potential treatments or interventions and how/where to access them
2. Was there any information you had a hard time getting from your provider or anything you weren't provided you would have liked to have been?

b. During this process, what types of information did healthcare providers ask you for or gather from you? Did you experience any difficulty providing it to them?
ii. Probes
1. *If they had difficulty providing any information*: What information and what made it difficult? How could this have been improved?
2. Did you feel comfortable sharing this information? What factors or circumstances affected your comfort level in providing this information?
3. Were you ever asked about prenatal alcohol exposure by any healthcare providers that weren't involved in the FASD evaluation? If so, who initiated this discussion and what questions did they ask?
4. *For Birth Parents*: Did you have any specific concerns or fears related to sharing information on prenatal alcohol exposure related to:
- Fear of judgement or stigma
- Fear of legal repercussions (e.g., CPS)

c. Can you describe any gaps in communication you experienced during the diagnostic journey or while accessing services? Do you have any suggestions about how this could be improved?
iii. Probes:
1. Can you elaborate on the specific instances where you felt there were gaps (e.g. between different healthcare professionals, with service providers, etc.)

2. What factors or reasons do you think contributed to these gaps (e.g. lack of information sharing, miscommunication, limited collaboration between professionals)

d. How did you share information about the diagnosis with:
   - Family members
   - Primary care providers
   - Educational institutions
   - Your child (if the child is older)

   iv. Probes
      1. What influenced your willingness to share, or not to share, this information?

5. Services

Structuring Statement: To conclude our conversation, let's shift our discussion to the services and recommendations that were offered for either your child or yourself as a caregiver. We'd like to better understand the support you received or were advised to seek as well as your thoughts on potential improvements in accessing services.

a. To begin, can you describe any interventions or services (e.g., medications, behavioral interventions, social services, etc.) that were recommended or provided for your child or to support you as a caregiver?
   i. Probes
      1. What are your thoughts on the effectiveness of these services?
b. Can you describe any facilitators or barriers to accessing and utilizing these services?
   i. Probes:
      1. Were there any financial or logistical challenges in accessing certain services?
      2. Were there any challenges you encountered related to navigating the healthcare system or obtaining referrals?
c. Can you suggest any improvements that would help address the barriers you faced in accessing services?
   i. Probes
      1. What changes in healthcare services or policies would have made the process smoother?

Appendix 3: Codebook

Evaluation and diagnostic process	Descriptions of how children are evaluated and diagnosed, including the criteria, how the provider ascertains the criteria. This is not where barriers/facilitators are described, however.
Barriers to evaluation/diagnostic process	Factors that delay, prevent, or hinder the completion of timely, effective, valid evaluation/diagnosis
Solutions to evaluation/diagnostic barriers	Actions/Approaches that providers take to overcome barriers to evaluation/diagnosis
Facilitators to evaluation/diagnostic process	Factors that support the completion of timely, effective, valid evaluation/diagnosis
Information received about child	Any evidence or information that the provider receives/seeks out about the child (hospital records, school records, etc.). Including information that helps the completion of timely, effective, valid FASD evaluation/diagnosis; also includes the processes through which providers receives this information
Barriers to receipt of information	Factors that delay, prevent, or hinder the timely receipt of valid information needed to evaluate/diagnose
Solutions to information barriers	Actions/approaches that providers take to overcome barriers to information receipt
Facilitators to receipt of information	Factors that support the timely receipt of valid information needed to evaluate/diagnose
Sharing diagnostic/evaluation results with others	Evidence that the provider sends out about the child's evaluation/ diagnosis to others; includes the process

	through which that information is shared or is documented into patients' records
Barriers to sharing diagnostic/evaluation results with others	Factors that delay, prevent, or hinder the timely sharing of valid evaluation/diagnostic information out to others; includes factors regarding documentation of evaluation/diagnostic information
Solutions to barriers to sharing evaluation/diagnostic results with others	Actions/approaches that providers take to overcome barriers to sending evaluation/diagnosis information out to others; including documenting evaluation/diagnosis information in patients' records
Facilitators to sharing diagnostic/evaluation results with others	Factors that support the timely sharing of diagnostic/evaluation results with others; including the documentation of diagnostic/evaluation results in patients' records