ASSESSING FASD IN YOUNG CHILDREN: EXPLORING CLINICAL COMPLEXITIES AND DIAGNOSTIC CHALLENGES

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ABSTRACT

Background
Children with fetal alcohol spectrum disorders (FASD) experience a range of cognitive, emotional, and behavioral challenges. Early assessment, diagnosis, and intervention are critical protective factors against adverse outcomes in FASD. However, FASD evaluations can be challenging in preschoolers and limited guidance is available to inform practice.

Objectives
We sought to describe the clinical presentation of preschool aged children assessed for FASD. Challenges encountered during the assessment process were also evaluated in order to inform the development of future diagnostic guidelines for clinicians undertaking FASD assessments in very young children.

Methods
Retrospective file information was coded for 72 children aged one to five assessed through the Glenrose Rehabilitation Hospital FASD Program using a structured coding manual. The sample included children who received an FASD diagnosis, children whose diagnosis was deferred, and children who did not receive an FASD diagnosis. Diagnostic findings, neurobehavioural functioning, past adversities and other clinical factors, and assessment recommendations were examined. Use of neurobehavioral assessment measures was also assessed.

Results
Young children diagnosed with FASD showed significant neurobehavioral impairment though clinical needs were high across the entire sample. High rates of pre- and postnatal adversity were seen in all children assessed. Use of objective tests to assess neurobehavioral functioning was limited, particularly among younger children.

Conclusions
Irrespective of diagnostic outcome, preschool aged children referred for FASD assessments presented with complex clinical profiles and significant needs. Findings highlight the challenges faced by clinicians and underscore the need for guidelines to direct clinical practice and training for interdisciplinary teams assessing preschool aged children with PAE.

Key Words: *Fetal alcohol spectrum disorder, preschool, assessment*

Fetal alcohol spectrum disorders (FASD) is an umbrella term that captures the range of physical, cognitive, and behavioral disabilities resulting from prenatal alcohol exposure (PAE).[1] FASD is associated with lifelong deficits and adverse outcomes[2], and is one of the most common known causes of preventable brain injury, with prevalence estimates ranging from 2 to 5% in school aged children[3]. Obtaining an accurate FASD diagnosis remains a challenging task,

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particularly in preschool aged children (ages 5 and under). The Canadian Guidelines for Diagnosing FASD[1] harmonize two popular approaches to evaluations following PAE, including the United States' Institute of Medicine (IOM) recommendations for diagnosing FAS[4] and the Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) 4-Digit Diagnostic Code system.[5] While neither of these approaches include explicit guidance for evaluating or diagnosing very young children, revisions of the Canadian Guidelines are underway and may provide additional clinical direction in this respect.[6]

The assessment of preschool aged children following PAE is fraught with challenges. Biopsychosocial development unfolds at a rapid pace during infancy and early childhood, and varies from child to child. Environmental influences play an important role in healthy development during these critical years.[7] Children with PAE are often raised in unstable caretaking situations and experience other environmental adversities at exceptionally high rates.[2,8,9] Early life adversities place children at risk for emotional and behavioral problems, however, there are still individual differences in response to adversities.[10] Importantly, when very young children experience significant adversity, trauma, or ongoing instability in the caretaking environment, evaluations of neurobehavioural functioning may not represent an accurate picture of their true capabilities. Evaluators may mistakenly ascribe deficits to PAE that may be the result of, or substantially exacerbated by, environmental factors. Later re-evaluations following amelioration of these conditions may result in a different profile of functioning for children that better reflects their strengths and limitations. Unfortunately, many children with FASD manifest both deficits associated with PAE and significant life adversities, placing them in "double jeopardy."[11] Irrespective of the etiological factors underlying problematic cognitive, behavioural, and emotional functioning in very young children, interventions are critical at this early point in development and thus warrant early assessment, even if the task is clinically challenging.

Another challenge in FASD assessments among very young children centres on the limited availability of standardized neuropsychological tests, largely because higher order domains of brain functioning, such as attention and executive functioning, are in early stages of development and are therefore difficult to assess.[12-19] This is particularly concerning given that preschoolers evaluated for FASD using age-appropriate tasks of executive functioning show significant impairment relative to age-matched non-exposed controls. This underscores the finding that neuropsychological deficits, and in particular problems with executive functions, may manifest before age six.[20]

Immature behavioral and psychological characteristics of preschool children may also limit their capacity to participate meaningfully in neuropsychological testing.[17,18] As a result, many areas of functioning are assessed by only questionnaire or caregiver report. Further complicating the assessment process, caregiver report questionnaires and objective tests of executive functioning show poor concordance in children with FASD and other neurodevelopmental disabilities (e.g., ADHD)[21,22] raising the possibility that parent report measures capture other aspects of neurobehavioral functioning and/or caregiver burnout. Without using objective tests to evaluate neuropsychological functioning, clinicians may only tap into part of the deficits underlying observed behavioral problems. Coupled with additional prenatal insults, undiagnosed medical conditions, and attachment problems, these factors can have a major impact on a child's presentation during the assessment process and in their day-to-day functioning.

Early assessment, diagnosis, and implementation of early interventions, are key protective factors against adverse outcomes in FASD.[2,10,23] Unfortunately, the availability of diagnostic services for children with PAE is limited in Canada.[1,24] Clinicians may be hesitant to undertake FASD assessments in young children as a result of inherent clinical challenges, however, failing to identify children at an early age may limit their developmental potential. Incorrect diagnoses rendered without sufficient professional

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guidance may result in inappropriately lowered developmental expectations and blunting of a child's potential. Further empirical data and clinical guidance is greatly needed to encourage and increase the availability of early assessment and diagnostic services for children with PAE, and also promote improved confidence and clinical reliability. We aimed to report data from ten years of clinical practice assessing preschool children with PAE for FASD at the Glenrose Rehabilitation Hospital (GRH) FASD Services program, in Edmonton Alberta. Clinical data about the neurobehavioral functioning of three groups of preschool children are presented, including those who received an FASD diagnosis, children who did not receive a diagnosis but were deferred for later reassessment, and children who did not receive a diagnosis. We also examined process data about the FASD assessment and recommendations offered during evaluations to inform clinical service needs. Early assessment and diagnosis play a key role in implementing appropriate supports and interventions that promote healthier future outcomes and reduce later life adversity following PAE. Therefore, refining the assessment process for preschool aged children with PAE is critical.

MATERIALS AND METHOD

Participants

Files were reviewed retrospectively for 70 preschool aged children (ages 1:0 – 5:9; M = 3.91, SD = 1.48) assessed for FASD through the GRH FASD Clinical Services Program between 2001 and 2010 (Table 1). Two-thirds of children were diagnosed with FASD (n = 45, 62.3%), nine (12.9%) had their diagnosis deferred, and one-quarter (n = 16, 22.9%) were not diagnosed. All children were referred for assessments by a primary care provider subsequent to concerns about PAE, combined with challenges in the child's emotional, developmental/cognitive, and/or behavioural presentation relative to same-aged peers. In some cases the diagnostic question of FASD is raised by the referring physician if there is a history of confirmed PAE. In other cases, the history of PAE is identified as part of the data gathering during the assessment process in clinic.

TABLE 1 Sample Characteristics by Group

	Diagnosed (n = 45)	Deferred (n = 9)	Not Diagnosed (n = 16)	Analyses
	M (SD) % (n)	M (SD) % (n)	M (SD) % (n)	
Age	4.33 (1.02)	2.99 (1.92)	3.25 (1.90)	F = 5.77**
1-1:11	2.2% (1)	33.3% (3)	38.0% (6)	
2-2:11	8.9% (4)	33.3% (3)	12.5% (2)	
3-3:11	17.8% (8)	0.0% (0)	6.3% (1)	
4-4:11	40.0% (18)	11.1% (1)	12.5% (2)	
5-5:11	31.1% (14)	22.2% (2)	31.3% (5)	
Gender (% male)	68.8% (31)	55.6% (5)	62.5% (10)	χ^2 = .69
Full Scale IQ	86.56 (8.79)	87.33 (9.29)	95.71 (10.53)	
(% assessed)	60.0% (27)	33.3% (3)	43.8% (7)	F = 2.81
Caregiver				
Biological Parent(s)	35.6% (16)	22.2% (2)	31.3% (5)	
Adoptive Parent(s)	11.1% (5)	55.6% (5)	6.3% (1)	χ^2 = 13.54*
Foster Parent(s)	37.8% (17)	11.1% (1)	50.0% (8)	
Other	15.6% (7)	11.1% (1)	12.5% (2)	
# Placements	2.95 (2.43)	3.00 (1.32)	2.63 (1.59)	F = .15
(range)	1-13	1-5	1-6	

Note: * p < .05, ** p < .01.

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The Diagnostic Process

The GRH FASD Clinical Services Program comprises an interdisciplinary diagnostic team typically involving a pediatrician, psychologist or neuropsychologist, occupational therapist, speech language pathologist, social worker/case manager, and clinical coordinator. Children in this sample were assessed over a one- to two-day period, involving medical, neuropsychological, and functional evaluations, diagnostic case conference, and family feedback sessions. PAE was confirmed in advance of each assessment for all participants and caregivers completed questionnaires in advance to expedite the clinic-day process. The University of Washington FAS DPN 4-digit coding system[5] was used to rank deficiencies across growth, facial phenotype, central nervous system (CNS), and PAE indicators, as well as other pre- and postnatal events and exposures. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale, with '1' reflecting complete absence of the FAS feature and '4' reflecting a strong "classic" presence. The diagnostic process involved differential consideration of other possible causes of deficits, such as complications from prematurity, birth asphyxia, genetic syndromes or abnormalities, or mental health disorders. When the clinical team deferred diagnosis and recommended future re-evaluation it was typically because significant environmental disruption, unaddressed trauma issues, or developmental concerns using standardized tests led to a confounded clinical picture. In such cases it was anticipated that the implementation of appropriate supports, stabilization of a child's caregiving situation, and/or developmental maturation would provide a more reliable view of his or her functioning at a future time.

The Canadian Guidelines[1] were also used as a model in the assessment process, particularly as a guide for evaluating CNS functioning. Nine domains of neurobehavioral function were assessed, including: hard and soft neurological signs, brain structure, cognition, communication, memory, executive functioning, attention, and adaptive behavior (academic functioning is not evaluated in preschool aged children). Following the Guidelines, a domain was considered impaired if scores fell at least two standard deviations below the mean and or if there was a discrepancy of at least one standard deviation between sub-domains. While three or more neurobehavioral domains must typically be impaired for an FASD diagnosis, the Canadian Guidelines provide a more liberal standard in preschool children by allowing for a CNS ranking of '2' to qualify (two domains of impairment).

Chart Reviews

Three research assistants and the lead author reviewed charts following a structured coding manual. Areas canvassed included clinical and family history, diagnostic findings, and data from assessments. Clinical recommendations were coded following Jirikowic, Gelo, and Astley's[25] system. All study procedures were approved by the University of Alberta Research Office of Research Ethics and adhered to governing ethical guidelines.

Diagnostic Coding and CNS Domain Classification

Diagnostic findings were coded from assessment records. Assessment approaches differed between cases and evolved over the ten-year period coded, thus, there was no ready method for comparing CNS findings across the entire sample. A standardized impairment rating scale was coded for each child following a thorough file review by the first author.[a] A code of "no impairment" (zero) was given when assessment data for a given domain fell within normal limits. A code of "mild to moderate impairment" (one) was assigned when assessment data fell between one and two standard deviations from the mean on psychometric test scores, or clinical judgment was described as "mild to moderate." Lastly, a code of "significant impairment" (two) was assigned when scores fell beyond two standard deviations (or psychometric test scores varied more than one standard deviation between subdomains, or within subtests on a measure) or clinical judgment was described as "significantly impaired." When

[a]The first author holds a PhD in Clinical Psychology and trained with the diagnostic team at Glenrose Rehabilitation Hospital FASD Clinical Services.

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insufficient data were present to rate a neurobehavioral domain it was not coded.

Adverse Childhood Event Scores

We created an adverse childhood experiences (ACE) total score by summing the presence of each of eight early life adversities, drawn from those coded in the Adverse Childhood Experiences (ACE) study[26], including child victimization factors (victim of physical, sexual, or emotional abuse, neglect, exposure to domestic violence) and parent characteristics (parent or sibling with mental illness, involved in the criminal justice system, substance abuse in the home). In the ACE study, scores of four or higher on the ACE scale were associated with significantly higher risk for illness and death, as well as poor quality of life.

Data Analysis

Descriptive data about participant demographics, diagnostic findings, neurobehavioral findings, and other clinical characteristics are presented to illustrate the complexity of this sample. Differences in demographic characteristics were assessed using *t*-tests and chi-square tests (for non-parametric data). Bivariate associations among diagnostic indicators were evaluated using Pearson correlations. As this is an exploratory study with a relatively small sample size, significance levels for all tests were set at $p = .05$. All analyses were conducted using IBM SPSS Statistics 22 for Mac.

RESULTS

Participants

Children in the three groups were similar across demographic characteristics with a few exceptions. Those who received a diagnosis were one year older, on average, compared to the deferred and diagnosed groups (Table 1). Of the 25 children who did not receive an FASD diagnosis, 10 (40.0%) had confirmed exposure to high levels of alcohol (rank 4). The three groups also differed with respect to caregiver status, with a higher proportion of the diagnosed group residing with biological parents.

Pre- and Postnatal Experiences

This sample was characterized by substantial rates of pre- and postnatal exposures across the diagnostic groups with little variability (Table 2). In terms of prenatal adversities, the majority of participants were exposed to nicotine, and/or additional drugs, including high rates of cocaine and marijuana exposure. Half of participants' mothers did not receive adequate prenatal care, many had labor and delivery problems, rates of premature births were high, and nearly one third were treated in a neonatal intensive care unit. Participants had similarly high rates of postnatal adversity and adverse childhood experiences. The mean ACE score for the overall sample was between three and four, with nearly half the sample endorsing four or more individual ACEs, and only one child reporting no ACEs. High rates of emotional, physical, and sexual abuse, neglect, and caregiver disruption were reported. In addition, many families were characterized by adversity themselves, including exceptionally high rates of substance abuse, domestic violence, justice system contact, or mental illness in a parent or sibling. Early concurrent medical conditions were also noted with frequency, including respiratory illnesses (41.7%), recurrent ENT infections (34.7%), seizure activity (6.9%), allergies/eczema (12.5%), and a range of other medical conditions (34.7%). Slightly less than one-third of children were taking medication at the time of their evaluation (29.1%), with many taking two or more medications concurrently (10%).

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TABLE 2 Rates of Pre and Postnatal Adversity are High Among Children Referred for FASD Evaluation

Prenatal Adversity	% (*n*)
Other Prenatal Exposures[a]	73.9 (51)
Nicotine	81.1 (56)
Cocaine	50.7 (35)
Marijuana	34.8 (24)
Other	44.9 (31)
Inadequate Prenatal Care	51.4 (36)
Labour/Delivery Problems	41.1 (29)
Prematurity	18.6 (13)
NICU	30.0 (21)
Postnatal Adversity	
ACE Score (0-8)[b] *M* (SD)	3.40 (1.71)
ACE Score 0	1.5 (1)
ACE Score 1 - 3	55.8 (38)
ACE Score 4 - 8	42.6 (29)
Child Factors	% (*n*)
Emotional Abuse	10.3 (7)
Physical Abuse	20.6 (14)
Sexual Abuse	11.8 (8)
Neglect	58.8 (40)
Caregiving Disruption[c]	78.6 (55)
Household Factors	
Substance Abuse	91.1 (62)
Domestic Violence	36.8 (25)
Justice System Contact	51.4 (35)
Mental Illness	88.2 (42)

Note: *N* = 68. [a]Other prenatal exposures does not include cigarettes/nicotine, only illegal street drugs and misuse of prescription medications were included. [b]Two participants were excluded from ACE score reporting owing to missing information on prenatal experiences. [c] = Not counted in the ACE score. ACE = Adverse Childhood Experiences; NICU = Neonatal Intensive Care Unit admission; PE = Prenatal Exposure.

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TABLE 3 Percentage of Children Scoring 1, 2, 3, or 4 in each Diagnostic Code Category by Group

		Ranking			
		1 % (*n*)	2 % (*n*)	3 % (*n*)	4 % (*n*)
Growth	FASD	86.7 (39)	2.2 (1)	0.0 (0)	11.1 (5)
	Deferred	66.7 (6)	22.2 (2)	0.0 (0)	11.1 (1)
	Not FASD	93.8 (15)	0.0 (0)	0.0 (0)	6.3 (1)
Face	FASD	66.7 (30)	26.7 (12)	6.7 (1)	0.0 (0)
	Deferred	66.7 (6)	11.1 (1)	11.1 (1)	11.1 (1)
	Not FASD	81.3 (13)	6.3 (1)	12.5 (2)	0.0 (0)
Brain (CNS)	FASD	0.0 (0)	60.0 (27)	35.6 (16)	4.4 (2)
	Deferred	11.1 (1)	88.9 (8)	0.0 (0)	0.0 (0)
	Not FASD	50.0 (8)	50.0 (8)	0.0 (0)	0.0 (0)
Alcohol	FASD	0.0 (0)	0.0 (0)	51.1 (23)	48.9 (22)
	Deferred	0.0 (0)	0.0 (0)	44.4 (4)	55.6 (5)
	Not FASD	0.0 (0)	0.0 (0)	54.3 (11)	45.7 (5)
Prenatal	FASD	2.2 (1)	2.2 (1)	48.9 (22)	46.7 (21)
	Deferred	0.0 (0)	0.0 (0)	22.2 (2)	77.8 (7)
	Not FASD	12.5 (2)	12.5 (2)	31.3 (5)	43.8 (7)
Postnatal	FASD	13.3 (6)	4.4 (2)	31.1 (14)	51.1 (23)
	Deferred	11.1 (1)	11.1 (1)	22.2 (2)	55.6 (5)
	Not FASD	31.3 (5)	0.0 (0)	11.1 (2)	56.3 (9)

Note: FASD *n* = 45; Deferred *n* = 9, Not FASD *n* = 16. Values in table reflect the distribution of each rank category *within* each diagnostic category. Codes for growth deficiency and facial features: 4-Severe, 3-Moderate, 2-Mild and 1-None; Brain (CNS) = Central nervous system, codes: 4-Definite, 3-Probable, 2-Possible and 1-Unlikely; Alcohol: 4-High risk, 3-Some risk, 2-Unknown and 1-No known risk; Pre- and Postnatal risk factors: 4-High risk, 3-Some risk; 2-Unknown risk; 1-No known risk[5]

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TABLE 4 Neurobehavioral Impairment by Domain in Children Assessed for FASD

		FASD	Deferred	Not Diagnosed
Domain		% (n)	*% (n)*	*% (n)*
	Assessed	93.3 (42)	88.9 (8)	93.8 (15)
Neurological Signs	None	35.6 (16)	33.3 (3)	66.7 (11)
(*n* = 63)	Mild-Mod	44.4 (20)	55.6 (5)	33.3 (5)
	Significant	20.0 (9)	11.1 (10)	0.0 (0)
	Assessed	100.0 (45)	100.0 (9)	100.0 (16)
Brain Structure	None	85.7 (36)	62.5 (5)	82.4 (13)
(*n* = 65)	Mild-Mod	2.4 (1)	25.0 (2)	5.9 (1)
	Significant	11.9 (5)	12.5 (1)	11.8 (1)
	Assessed	93.3 (42)	6 (66.7)	87.5 (14)
Cognition (IQ)	None	38.1 (16)	33.3 (2)	87.5 (12)
(*n* = 58)	Mild-Mod	26.2 (11)	0.0 (0)	12.5 (2)
	Significant	35.7 (15)	66.7 (4)	0.0 (0)
	Assessed	77.8 (35)	44.4 (4)	43.8 (7)
Attention	None	5.7 (2)	0.0 (0)	25.0 (1)
(*n* = 43)	Mild-Mod	17.1 (6)	0.0 (0)	0.0 (0)
	Significant	77.1 (27)	100.0 (4)	75.0 (6)
	Assessed	15.6 (7)	11.1 (1)	6.3 (1)
Memory	None	33.3 (2)	100.0 (1)	100.0 (1)
(*n* = 6)	Mild-Mod	16.7 (1)	0.0 (0)	0.0 (0)
	Significant	50.0 (3)	0.0 (0)	0.0 (0)
	Assessed	66.7 (30)	33.3 (3)	25.0 (4)
Executive Function	None	0.0 (0)	0.0 (0)	0.0 (0)
(*n* = 34)	Mild-Mod	10.0 (3)	0.0 (0)	50.0 (2)
	Significant	90.0 (27)	100.0 (3)	50.0 (2)
	Assessed	32 (71.1)	44.4 (4)	68.8 (11)
Adaptive Function	None	18.8 (6)	50.0 (2)	75.0 (8)
(*n* = 44)	Mild-Mod	34.4 (11)	25.0 (1)	16.7 (2)
	Significant	46.9 (15)	25.0 (1)	8.3 (1)
	Assessed	97.8 (44)	100.0 (9)	100.0 (16)
Communication	None	4.5 (2)	20.0 (2)	31.2 (5)
(*n* = 62)	Mild-Mod	31.8 (14)	40.0 (4)	50.0 (8)
	Significant	63.6 (28)	40.0 (4)	18.8 (3)

Note: "Assessed" indicates the number and percent of participants in each diagnostic group evaluated on a given domain.

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Diagnostic Characteristics

Among children diagnosed with FASD, Neurobehavioral Disorder (*n* = 29, 64.4%) was the most common diagnosis, followed by Static Encephalopathy (*n* = 14, 31.1%). Only two children (4.4%) received a diagnosis of Partial FAS (in accordance with the FAS DPN four-digit code).[5] Diagnostic profiles are presented in Table 3. Across the sample, very few children had significantly impacted (scores of 3 or 4) growth (*n* = 7, 13.9%) or facial characteristics (*n* = 7, 13.9%), in spite of significant PAE (*n* = 70, 93.3%). A substantial number of children across the three groups (60% of the FASD group, 89% of deferred group, and 50% of the non-diagnosed group) presented with only mild to moderately impaired CNS scores (CNS code 2). Nine children (13%) presented with no measurable PAE-related deficits in growth, facial features, and CNS functioning, despite confirmed PAE with unclear exposure levels (*n* = 7) and confirmed heavy exposure levels (*n* = 2).

Several clear indicators of neurobehavioral impairment were evident among children who received an FASD diagnosis (Table 4). The majority had significantly impaired executive functioning and communication skills. Nearly half showed impairments in adaptive functioning, and more than one-third had impaired intellectual functioning. Few children who received an FASD diagnosis presented with significant neurological signs or structural deficits. The majority of diagnosed children had three or more significantly impacted neurobehavioral domains (*n* = 27, 64.3%), although nearly a third (*n* =13, 31.0%) had only two impacted domains. Few deferred children (*n* = 2, 22.2%) had three or more domains of impaired functioning, and three children (33.3%) had two impacted domains.

Patterns of neurobehavioral functioning between the diagnosed and deferred groups showed concordance in certain areas. The majority of children in these groups showed mild to moderate or significant deficits in executive functioning, attention, and communication. Both groups also showed more variable performance on measures of intellectual functioning and adaptive functioning. In keeping with expectations, children who did not receive an FASD diagnosis had better overall functioning across neurobehavioral domains, though some variability was evident. A subset of children (*n* = 10, 14%) who did not receive a diagnosis or had their diagnosis deferred presented with high PAE levels (PAE rank = 4). Of these, two (20.0%) had significant growth restriction, three (30.0%) had significant dysmorphic facial features, but none were assessed as having sufficient CNS impairment to warrant a diagnosis (CNS code = < 3). This group was also younger, on average, relative to the overall sample, with a mean age of 2.78 (*SD* = 5.7), *t* (68) = 2.71, *p* = .008, with six children from this group (60.0%) being age one or two.

Recommendations from the Assessment

The most common recommendation, irrespective of diagnostic group, involved anticipatory guidance around preventing or mitigating difficulties in future learning and risk for behavioral problems (see Table 5). Recommendations for further assessment or treatment with a speech language pathologist or occupational therapist, and/or physician for medication evaluation, were next most common. Recommendations about the importance of advocating for child welfare placement stability and caregiving families were also frequent. Overall, a wide range of future assessments and supports were recommended across educational and medical settings, suggesting the assessment team identified what are likely significant and long-lasting patterns of clinical needs in this population. The rate at which clinicians advocated various recommendations was comparable across the three groups indicating high clinical and resource needs among all children with PAE, irrespective of diagnostic outcome.

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TABLE 5 Intervention Recommendations are Comparable among Children Referred for FASD Assessments

Intervention Category	Specific Recommendation	FASD	Deferred	Not diagnosed	Total
		n (%)	*n* (%)	*n* (%)	*n* (%)
Anticipatory Guidance/Prevention	Learning Problems/Behavior risk	75.6 (34)	55.6 (5)	81.3 (13)	70.8 (51)
Developmental Therapy	OT/SLP Evaluation/Treatment	48.9 (22)	66.7 (6)	43.8 (7)	48.6 (35)
Medical	Psychiatric and/or meds	55.6 (25)	33.3 (3)	25.0 (4)	44.4 (32)
Social Service/Child Welfare	Placement advocacy	35.6 (16)	55.6 (5)	22.2 (10)	43.1 (31)
Family Support/Resources	Advocacy/Education	37.8 (17)	33.3 (3)	50.0 (28)	38.9 (28)
Education/Assessment	Assessment to determine eligibility	40.0 (18)	44.4 (4)	37.5 (27)	37.5 (27)
Medical	Vision/Hearing evaluation	31.1 (14)	33.3 (3)	37.5 (27)	37.5 (27)
Education/Assessment	Apply for funding	51.1 (23)	11.1 (1)	36.1 (26)	36.1 (26)
Other	FASD re-evaluation/Another GRH assessment	22.2 (10	55.6 (5)	43.8 (7)	30.6 (22)
Education/Assessment	Educational services	33.3 (15)	44.4 (4)	12.5 (2)	29.2 (21)
Education/Assessment	IPP/Modify program/expectations	35.6 (16)	11.1 (1)	25.0 (4)	29.2 (21)
Family Support/Resources	Respite/Self-care for caregiver	35.6 (16)	11.1 (1)	12.5 (2)	26.4 (19)
Accommodations	Communication	28.9 (13)	22.2 (2)	18.8 (3)	25.0 (18)
Accommodations	Behavior/Emotional regulation	24.4 (11)	33.3 (3)	18.8 (3)	23.6 (17)
Accommodations	Sensory motor	26.7 (12)	22.2 (2)	168.8 (3)	23.6 (17)
Education/Assessment	Early school-based intervention program	28.9 (13)	22.2 (2)	12.5 (2)	23.6 (17)

Note: Specific recommendations by intervention category are listed in rank order from most to least recommended across the entire sample. FASD *n* = 45. Deferred *n* = 9. Not diagnosed *n* = 16. Only the most common recommendations are listed.

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TABLE 6 Commonly Used Psychometric Assessment Tools to Evaluate Neurobehavioral Domains

Domain	Test	Administered	Reviewed	Total
Intellectual functioning	WPPSI (R. or 3rd Ed)	39	1	40
	Bayley Scales of Infant Development (2nd Ed)	24		24
	McCarthy Scales of Children's Abilities	5		5
	Pictorial Test of Intelligence	2		2
Attention/ Memory	Conners Rating Scales (parent or teacher)	26		26
	Wide Range Assessment of Memory and Learning	4		4
	NEPSY (1st or 2nd Ed)	13		13
	California Verbal Learning Test - Children's version?	5		5
Executive Functions	BRIEF Parent or Teacher Report	20		20
	NEPSY (1st or 2nd Ed)	12		12
Adaptive functioning	ABAS-II Parent or Teacher Report	16		16
	Vineland Adaptive Behavior Scales	10		10
	Scales of Independent Behaviour	5		5
	Behavioral Assessment Screening Checklist - 2nd Edition	5	2	7
Language	Preschool Language Scale	21	8	29
	Rossetti Infant Toddler Language Scale	19		19
	Preschool Language Assessment Instrument	16	1	17
	Test of Language Development (3rd Ed)	14		14
	Expressive Language Test	11	1	12
Motor Skills & Sensory	Peabody Infant Development Motor Scales - 2nd Edition	45	10	55
	Short or Long form Sensory Profile	20	1	21
	Beery Developmental Test of Motor Visual Integration (4th & 5th Ed)	20		20
	Bruinicks-Oseretsky Test of Motor Proficiency (1st & 2nd Ed)	6		6
	Motor Free Visual Perception Test - Revised	6		6

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Use of Tests

Use of objective psychometric measures to assess neurobehavioral functioning varied across assessments but were most commonly used to assess general intellectual ability (IQ) (n = 63, 90.0%), communication/language (n = 66, 94.3%), and fine and gross motor skills (n = 62, 88.6%), (Table 2). Memory was rarely formally evaluated (n = 8, 11.4%). Neuropsychological tests and questionnaires were used more often to assess attention (n = 26, 37.0%), executive functioning (n = 20, 28.56%), and adaptive functioning (n = 29, 41.4%). Use of questionnaires (vs. objective measures) was more common across areas of higher order functioning, including attention, executive, and adaptive functioning. Because psychometric testing is much more complex and difficult with the youngest children (ages one and two), we evaluated whether test use varied between younger and older preschool aged children. As expected, compared to older children, those ages one and two were significantly less likely to have completed tests evaluating intellectual functioning (73.7% vs. 94.1%), χ^2 (1) = 5.71, p = .02, attention (0.0% vs. 51.0%), χ^2 (1) = 15.41, p < .001, or executive functioning (0.0% vs. 39.2%), χ^2 (1) = 10.43, p = .001. Fewer of the younger children were evaluated on memory (0.0% vs. 15.7%, p = .07), or adaptive functioning (22.2% vs. 47.1%, p = .07) compared to older children, though these trends were not significant. Alternatively, younger children were formally evaluated using objective measures with more comparable frequency on language skills (100.0% vs. 90.2%) and motor skills (78.9% vs. 90.2%) relative to older children.

DISCUSSION

The goal of this research was to examine the clinical profile of preschool aged children evaluated for FASD and report on the experiences and challenges inherent in FASD assessments undertaken at the GRH FASD Program over a ten-year period. It is hoped that these data and experiences will inform the development of practice standards for assessments following PAE in very young children, and stimulate further research and conversation. In keeping with prior studies evaluating the characteristics of infants and children with PAE[20,27], we found significant neurobehavioural impairment in those who received an FASD diagnosis. As would be expected from a clinically referred sample, we also found high rates of impairment and clinical need across children irrespective of diagnostic outcome. These findings have important implications for the delivery of assessment and intervention services in this vulnerable group of young children.

Despite concerns about diagnostic accuracy, children who received an FASD diagnosis displayed a profile of neurobehavioral impairment consistent with deficits identified in other samples of infants and toddlers[20,27,28] and older children and adolescents with FASD[29-34], including deficits in overall intellectual ability (IQ), executive functioning, adaptive functioning, and communication.[29-34] As expected rates of neurobehavioral impairment were higher in children who received an FASD diagnosis, relative to deferred and non-diagnosed children. Interestingly, nearly 15% of our sample was classified as having confirmed high levels of PAE (rank 4), but were either not diagnosed or deferred for re-evaluation. Many of these children were ages one and two, ages at which only limited objective, standardized assessment can be undertaken in most CNS domains. In addition, many children (n = 9, 13.0%) with confirmed PAE did not present with measurable deficits in growth, facial features, or sufficient impairment across CNS domains to warrant ranks of two, three, or four following the 4-digit code, consistent with other studies finding that a subset of children with PAE do not present with measurable deficits (e.g., Astley, 2010). These findings highlight the importance of conducting careful and rigorous evaluations during FASD assessments. Importantly however, it is possible that these children, especially, the youngest among them, may be have been too young for significant deficits in CNS functioning to emerge following available assessment protocols.

Although our young FASD sample presented similarly to other samples of children with FASD in the literature, numerous clinical challenges complicated the diagnostic process for

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clinicians attempting to render reliable and accurate diagnoses. In keeping with previous studies[2,23] pre- and postnatal complications beyond PAE, including drug exposures, poor prenatal care, lack of caregiving stability, and adverse childhood experiences were observed at high rates in this sample. Clinicians opted to defer diagnosis for nearly 10% of children in this study, suggesting that these factors, combined with age, likely impacted differential decision making for a subset of children assessed. Rates of adversity across this sample underscore the challenges inherent in differentiating the etiological underpinnings of observed deficits across children referred for evaluation. These findings highlight the importance of ensuring that interdisciplinary teams conducting FASD assessments receive training on the impact of additional of pre- and postnatal influences on development and functioning. Guidelines advising assessment teams regarding how to proceed when confronted with these issues would promote more reliable and effective clinical practice in diagnosing preschoolers with FASD.

As expected, objective assessment tools and tests were used with varying frequency. While rates of test use were lower among infants and toddlers in this sample, test use also varied among preschool aged children. This finding highlights the possibility that children in general, and perhaps in particular those with significant clinical issues prompting diagnostic referral, vary in their capacity to undergo structured standardized testing. Other factors that may have influenced test use include institutional or system level barriers to evaluation, including the short assessment window available during which a child could complete testing. In practical terms, evaluators have a limited amount of time to complete an assessment in publicly funded settings and practical demands often require being selective and strategic in decisions about what tests to administer and domains to evaluate in more or less depth, based on the presentation of each child referred for assessment. Combined, these factors highlight the difficulty evaluators may face in accurately assessing the neurobehavioural domains in young children, which may contribute to a lack of diagnostic clarity. Given that standardized tests were not used across all neurobehavioral domains, clinicians relied heavily on clinical judgment in their evaluations. Guidelines directing clinicians on relevant factors to consider or steps to be taken would aid in this regard.

Rates of neurobehavioral deficits and clinical needs across this sample were exceptionally high. Regardless of the complexity of rendering a diagnosis among preschoolers, these findings underscore the importance of conducting early functional assessments (even if they cannot be given a formal diagnosis of FASD at the time of assessment) in children who present with confirmed PAE and developmental, cognitive, behavioral, or social challenges to inform the delivery of early intervention plans. Previous research in our laboratory has shown that earlier assessments (not necessarily a diagnosis) are associated with better outcomes in children with PAE.[23] Implementation of clinically-informed interventions are also critical for optimizing developmental potential, preventing secondary trauma, and mitigating strain on caregiving relationships.[10,35-37] Although the issue remains controversial, service delivery may not need to be diagnosis-driven in this age group. We saw that clinicians made comparable recommendations for intervention in children who received a diagnosis and those who did not. This finding suggests that individual functional deficits, rather than diagnosis, guided clinician decision making about necessary supports and treatment protocols. Recommendations were also consistent with those found in an American sample of preschool and school aged children diagnosed with FASD.[25] Although it is helpful to observe consistency in this respect, it tells us little about whether recommendations were implemented or if families were able to access necessary supports after the assessment. Future longitudinal research following children after PAE-related assessments is needed, as appropriate services are limited for children with FASD across Canada and it remains unclear whether families receive sufficient support to access available services.

In keeping with other studies, few children in this sample presented with physical indicators of FASD[38-40], underscoring the

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importance of carefully assessing neurobehavioral functioning in preschool aged children. Understanding the functional presentation of a child alongside underlying neurobehavioral deficits represents the key driving factor in making informed recommendations around intervention and service delivery. Nevertheless, assessing neurobehavioral functioning in very young children remains a significant challenge. In the present sample many neurobehavioral domains were assessed using questionnaires based on parent/caregiver reports, while objective, standardized measures of functioning were used intermittently. Further, it is often the case that a single informant may rate a child on multiple questionnaires, proving to be a very influential single collateral source of information about the child. Alternatively, sometimes clinicians must also interpret conflicting behavioural reports from multiple informants using the same tools to rate a child's functioning. In either case, using only questionnaires may not effectively tap into all relevant aspects of a given area of neurobehavioral functioning and may lead to an inaccurate clinical picture for a young child undergoing assessment. Given the limited availability and high cost of diagnostic services for FASD in Canada, it is critical that a complete and accurate clinical picture is captured as opportunities for later re-evaluation may be limited. Objective assessment tools used to assess communication and motor functioning were used most often in this sample, and in particular at higher rates in the youngest children, suggesting that speech language pathologists and occupational therapists played an important role in assessing functioning in preschoolers. Indeed, their assessments appeared to support and augment the limited testing capacity of neuropsychologists in this age group. Nevertheless, the fact that the many neurobehavioral domains were assessed with intermittent regularity highlights the need for further specific guidelines to inform assessment and diagnostic practices for PAE in very young children.

Limitations

This study had several limitations. Although using a retrospective chart review allowed us to access a rich clinical dataset, our findings are limited by the scope of information included in patient charts. Although the GRH FASD program records extensive clinical information, these data may not capture the true clinical picture of observed needs and deficits in all children. Prospective research following a larger cohort of preschoolers through and beyond the assessment process would yield more reliable findings and augment generalizability of the present results.

Our sample was also one best characterized as "clinically complex." Although much of the research evaluating functioning in individuals with FASD is comparable in this regard, it is nevertheless possible that our clinically referred sample limits the generalizability of these findings and recommendations to the full spectrum of young children with PAE. It is possible that children with less severe clinical profiles function better during this developmental period and may not hit the radar of referral sources until a later age when day-to-day demands intensify (e.g., midway through primary school). Likewise, infants with obvious physical impacts from heavy PAE such as dysmorphic facial features and growth restriction are likely referred to address FAS-related complications closer to birth. Overall, this sample is likely representative of the preschool aged children seen by interdisciplinary teams in clinical settings where social determinants of health interact to produce both prenatal alcohol use and poor pre- and postnatal care environments for children and their families.[41,42]

Lastly, differences in clinical practice and test use required us to use a post-hoc coding scheme to compare neurobehavioral functioning. This may have yielded findings different from the nuanced interpretations clinicians may have made. Information for domains was often missing, which we attributed as a lack of assessment in a given area. Thus, it is possible that our findings may not accurately capture functioning in all children sampled. Interdisciplinary teams who hope to evaluate the profiles and functioning of children seen through their clinics in future research would

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benefit from following a standardized recording scheme at the time of assessments.

Policy and Practice Implications

Findings from this cohort of preschool aged children reinforces suspicions about the clinical complexity inherent in undertaking FASD assessment and diagnosis in this age group. Much work remains to be done in developing a consensus regarding diagnostic practices in very young children. As national calls for improved access to assessment and diagnosis continue to circulate[43] it is apparent that a working group is needed to propose reliable consensus guidelines and to develop a best practice model of FASD assessment and diagnosis in preschool aged children. All children with PAE need ongoing access to developmental and medical care as they are at risk for emerging learning difficulties at older ages, mental health concerns and physical health conditions. Adverse childhood experiences also increase those same risks. A recent paper, Anticipatory Guidance for Children and Adolescents with Fetal Alcohol Spectrum Disorder (FASD): Practice Points for Primary Health Care Providers outlines the needs at various age groups for the PAE population.[44]

The question of whether to diagnose FASD in preschool aged children is a contentious one. Findings from this study were used to help develop evidence-based guidelines for preschool assessments at the GRH FASD Services Clinic. Specifically, preschool aged children are no longer seen in the FASD clinic, owing largely to limited capacity (65-70 assessments per year) and the high costs of an interdisciplinary FASD assessment. Forced with economic constraints, clinicians have opted to focus on older children once neurobehavioral domains of functioning have stabilized and tools are available to reliably assess functioning. An interdisciplinary team dedicated to general developmental and behavioral problems in preschoolers now assesses all preschool aged children with neurodevelopmental and behavioral problems, including those with PAE. After this initial assessment, those with confirmed PAE are referred to the FASD clinic for a planned future reassessment. In the meantime the role of the social worker assigned to the FASD clinic has been expanded, with increased time dedicated to assisting caregivers and families who require support and connection with FASD specific programming and resources. This two-phase assessment process provides important early access to functional assessment and developmentally-driven clinical services, FASD-specific support connections, and a mechanism for later assessment once deficits in functioning have stabilized.

The GRH solution to preschool FASD assessment highlights the importance of reassessment. Preschool aged children diagnosed with an FASD may demonstrate significant change in their clinical profile as a result of both developmental and environmental influences. In addition, results from a preschool years assessment will likely not capture changing developmental needs in later childhood and adolescence. Thus, there is a strong need to reassess functioning over time. Several points in development represent potentially critical periods, including transitions to middle school, high school, and adulthood. Policy makers should be aware of this dilemma, in light of the costs associated with FASD assessments, and the importance of planning for the needs of individuals with FASD in adult services.

Findings from this study represent one of few efforts to understand the clinical characteristics and neurobehavioral profile of functioning in preschool aged children presenting for FASD assessments. Although early assessment plays a critical role in timely referral for interventions, the challenges inherent in assessing and diagnosing preschool aged children with PAE highlighted in this study underscore the need for better guidance in the field. Interdisciplinary teams conducting assessments with preschool aged children who have PAE and other pre- and postnatal adversities would benefit from training across areas identified, as well as guidelines to direct clinical practice. Policy changes at the GRH FASD clinic represent one possible solution for ensuring preschoolers receive both early assessments, and later reassessment for FASD. However, further discussion among diagnostic experts and the development of consensus

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guidelines would benefit clinicians grappling with these complex issues.

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