

FETAL ALCOHOL SPECTRUM DISORDER: DIAGNOSTIC OUTCOMES IN
NORTHEASTERN ONTARIO

by

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Abstract

The current document is a paper-based thesis examining the diagnostic outcomes of children and youth who presented for Fetal Alcohol Spectrum Disorder (FASD) assessment in Northeastern Ontario. While past research has identified many functional difficulties and challenges that are associated with FASD, little is currently known about this population in Northeastern Ontario. Therefore, as part of a nation-wide FASD initiative conducted by the Canada FASD Research Network (CanFASD), the current study employed a retrospective chart review and secondary data analysis of children and youth who have been assessed for FASD at the Sudbury FASD Diagnostic clinic, which services the Northeastern Ontario region. The first paper is a descriptive overview of those who presented for FASD assessment, and further compares the individuals who received an FASD diagnosis and those who did not. Findings demonstrate a need to support individuals with prenatal alcohol exposure through multiple service entities within the region. The second paper examines the intelligence quotient (IQ) scores and related adverse outcomes among the children and youth in the sample who received an FASD diagnosis. Findings support the known weakness with IQ in describing the difficulties and needs of individuals with FASD, and further highlight the importance of an early diagnosis to lessen the risk of adverse outcomes. Suggestions for future research and clinical implications are also discussed.

Keywords:

The following could be used to describe this thesis entitled "Fetal Alcohol Spectrum Disorder: Diagnostic Outcomes in Northeastern Ontario", which examines the diagnostic outcomes at the FASD Diagnostic Clinic in Sudbury, Ontario: fetal alcohol spectrum disorder, Northeastern Ontario, developmental disability, prenatal alcohol exposure, diagnosis, outcomes, service needs, assessment, assessment and diagnosis.

Statement Of Co-Authorship

I declare that this thesis includes materials that are a result of joint research collaborations. The following includes a list of the publications containing material produced in this thesis, with the nature and scope of work from co-authors.

Burns, J. I., Coons-Harding, K. D., Watson, S. L., Cook, J., & Unsworth, K. (in preparation).

Fetal Alcohol Spectrum Disorder in Northeastern Ontario: A descriptive examination of who is assessed, who receives a diagnosis, and who does not. *Journal on Developmental Disabilities*.

Burns, J. I., Coons-Harding, K. D., Watson, S. L., Cook, J., & Unsworth, K. (in preparation).

Examining the intelligence quotients and related adverse outcomes among a Northeastern Ontario sample of children and youth with Fetal Alcohol Spectrum Disorder. *Journal of Intellectual Disability Research*.

The following contributions apply to both manuscripts listed above.

J. I. Burns developed the research questions, acquired the data, conducted the secondary data analysis, and wrote the majority of the manuscripts.

K. D. Coons and S. L. Watson were the Master's supervisors supporting the primary investigator (J. I. Burns), and provided extensive feedback and revisions for both documents.

J. Cook and K. Unsworth were responsible for the creation of the National FASD Database, through which data for the current study was obtained, and they continue to facilitate the collection of data for the larger project with all participating clinics in Canada.

I certify that this thesis, and the research to which it refers, is the product of my own work.

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Chapter 1: Introduction

Researchers have demonstrated that individuals with Fetal Alcohol Spectrum Disorder (FASD) experience very unique difficulties and challenges, which often warrant them to receive lifelong support and intervention (Carr, Agnihotri, & Keightley, 2010; Chudley, 2017; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Despite a growing wealth of literature examining the direct experience of those with FASD, research using a Canadian sample, and more specifically examining individuals in Northeastern Ontario, is extremely limited or lacking altogether. Moreover, given the geographical nature of Northeastern Ontario, issues such as access to health care services, lack of culturally appropriate care, and increased mental health challenges have all been reported as additional challenges for individuals living in the region (Al-hamad & O’Gorman, 2015). Therefore, it is important to recognize and address service needs and availabilities for populations, like those with FASD, where there is an increased and unique need for services and supports. Past research in Northern Ontario pointed to a lack of FASD-informed services, supports, and management interventions, and families of individuals with FASD reported feeling both under supported and misunderstood (Watson, Hayes, Coons, & Radford-Paz, 2013).

In 2015, Clarren and colleagues published results from a pilot study using a standardized questionnaire to examine the frequency and patterns of specific deficits, common diagnoses, and typical recommendations provided to individuals assessed for FASD across various diagnostic clinics in Canada. Results indicated that the diagnostic experience of evaluating this population was similar across provinces, that continual collection of this data could be particularly useful in describing the unique needs among Canadians with FASD, and that this information could assist in improving access to and delivery of services. This project, now referred to as the National

FASD Database project, led by the Canada FASD Research Network (CanFASD), is the first and only project in the world to gather FASD-related information from multiple sites using an online forum. As of June 2019, 29 FASD clinics across Canada were entering data and more than 2000 client records had been inputted (Canada FASD Research Network, 2019). The Database (see Appendix A) captures information specific to areas including, but not limited to: demographics; the referral reasons; presenting concerns; diagnosis; assessments and; co-occurring mental health concerns. In collaboration with the National FASD Database project, the current study aimed to address the gap in the literature by providing current and comprehensive information on individuals prenatally exposed to alcohol in Northeastern Ontario who present for an FASD assessment. Findings also speak to the unique differences among individuals who received an FASD diagnosis and those who did not in order to inform service needs.

1.1 Fetal Alcohol Spectrum Disorder

FASD is the diagnostic term used to describe the range of physical, mental, behavioural, and learning impairments that can result from prenatal alcohol exposure (Cook et al., 2016). Individuals with FASD experience a wide range of difficulties, which often have direct implications on their everyday functioning (Chudley, 2017). For example, memory and impulse control deficits can negatively influence one's decision making and planning abilities (Brown et al., 2018). Families of individuals with FASD often share in these challenges and have been found to experience distinct struggles themselves (Coons, Watson, Yantzi, & Schinke, 2016; Michaud & Temple, 2013; Watson, Hayes, Coons, et al., 2013). More specifically, caregivers report significant stress from the demands placed on them, high levels of worry regarding their child's future, and many face the reality of the social stigma that surrounds FASD (Corrigan et al., 2018; Michaud & Temple, 2013; Watson, Hayes, Coons, et al., 2013).

1.1.2 Prevalence. In the Western world, FASD is the leading cause of developmental disability and, with the help of proper preventative measures, is believed to be largely preventable (Popova et al., 2017; Rasmussen et al., 2008). Though variability exists in how FASD is recognized and subsequently diagnosed, the disorder itself is universally prevalent (Kalberg & Buckley, 2007; Lange et al., 2017; Popova, Lange, Probst, Gmel, & Rehm, 2017). In saying this, within Canada established diagnostic guidelines for FASD exist, which serve to enhance both the consistency and accuracy of diagnosing the disorder (Coons-Harding, Flannigan, Burns, Rajani, & Symes, 2019). The commonly accepted prevalence rate in Canada is suggested to be 4% in the general population (Flannigan, Unsworth, & Harding, 2018). Based on findings from a recent study conducted in the Greater Toronto Area, researchers suggest that between 2-3% of elementary aged students living in the region meet diagnostic criteria for FASD (Popova, Lange, Chudley, Reynolds, & Rehm, 2018).

Findings support elevated rates of FASD in both rural and remote Ontario communities (Tough, Ediger, Hicks, & Clarke, 2008), however a lack of research on the prevalence of FASD in these geographical areas, including Northeastern Ontario, limits our understanding on the exact proportion of the population with the disorder. Additional issues such as access to the diagnostic service and extensive wait times once connected to the service, which are particularly relevant in rural and remote locations, may also influence prevalence estimates (Paley & O'Connor, 2011; Watson, Hayes, Coons et al., 2013). Despite noted variability among prevalence rates, it is a commonly shared belief by researchers that the prevalence of FASD is largely underestimated due to several challenges involved in the diagnostic process, as well as the “invisible” nature of the disorder (Chudley, 2008; Flannigan et al., 2018; Paley & O'Connor, 2011).

1.1.3 Features and characteristics. Though FASD is largely an invisible disability, it can have unique visible characteristics which, when simultaneously present in an individual indicate that he or she has been exposed to alcohol prenatally (Cook et al., 2016). These physical characteristics include three distinct facial features involving the eyes and mid-face and are commonly referred to as “sentinel facial features” (Chudley et al., 2005). They are further described as short palpebral fissures (length of the eyes), a smooth philtrum (space between upper lip and nose), and a thin vermilion border of the upper lip. These features, when presented together, can be particularly useful for medical professionals in identifying individuals who may be at risk for FASD as well as informing a diagnosis (Cook et al., 2016). However, few individuals with FASD present with all three sentinel features, while a large majority have none at all (Benz, Rasmussen, & Andrew, 2009). For example, in one Canadian study examining 50 children with FASD, only 18% presented with some indication of these features, while the remaining 82% had no facial abnormalities (Rasmussen, Horne, & Witol, 2006). Likewise, a recent update from the CanFASD National Database project revealed that in the sample of over 900 individuals diagnosed with FASD, close to 45% had no facial abnormalities while approximately 12% presented with all three features (Cook, 2019).

Most evident in individuals with FASD are the deficits in both cognitive and behavioural functioning; a byproduct of alcohol’s direct impact on the structural and functional development of the brain (Burd, Blair, & Dropps, 2012; Paolozza, 2015). The cognitive deficits noted among this population range in severity, with more pronounced weaknesses having significant repercussions on one’s adjustment, independence, and abilities (Greenbaum, Stevens, Nash, & Koren, 2009). Areas of difficulty often include learning, academic achievement, language, social communication, executive functioning, and memory (Greenbaum et al., 2009; Mattson, Crocker,

& Nguyen, 2011). Thus, on an average day, an individual with FASD may have difficulty memorizing information and may seem forgetful, they may struggle understanding lengthy instructions or conversations, they may be more likely to repeat their past mistakes, and they may have difficulty managing their time and behaviour (McLachlan & Rasmussen, 2018).

The impulsive tendencies, poor judgment, and difficulties understanding the consequences of actions that may be more prevalent with individuals with FASD can leave them extremely vulnerable to high-risk behaviours and the potential adverse life outcomes that can occur as a result (Greenbaum et al., 2009; Rasmussen et al., 2008). Thus, maladaptive behaviours such as bullying, lying, stealing, and cheating, as well as aggressive, antisocial, and disruptive classroom behaviours are frequently reported among this population (Rasmussen et al., 2008; Rasmussen, Talwar, Loomes, & Andrew, 2008). For example, in one study children with FASD as young as 4 years old were found to display more frequent deviant behaviours, such as lying, compared to typically developing children (Rasmussen, Talwar, Loomes, et al., 2008). Individuals with FASD may also have difficulty processing the information and stimuli around them, increasing their sensitivity and reactions to various sensory inputs (e.g., becoming physically aggressive due to excessive or loud noises; Brown et al., 2018; Carr et al., 2010). Additionally, deficits in social functioning, which can make appreciating the actions or feelings of another person difficult, increases an individual with FASD's vulnerability to manipulation and persuasion (Rasmussen et al., 2008). In one Canadian study, 92% of individuals with FASD were described by their caretakers to be vulnerable to manipulation (Clark, Lutke, Minnes, & Ouellette- Kuntz, 2004). It has been suggested that this level of vulnerability, along with the inability to think in a cause and effect manner, can lead to the many high-risk behaviours and related difficulties with the law seen in individuals with FASD (Rasmussen et al., 2008).

1.1.4 Intellectual functioning. Individuals with FASD have been found to vary in their intellectual functioning, with many presenting with average intelligence (Kingdon, Cardoso, & McGrath, 2016). What often becomes problematic for these individuals is that deficits in other areas pertinent to everyday functioning, such as adaptive living skills, are often well below what would be expected with an average IQ (Fryer, McGee, Matt, Riley, & Mattson, 2007; Mattson et al., 2011; Streissguth et al., 2004). In such cases, obtaining services that are comprehensive and lifelong, like developmental services, becomes an added challenge when IQ's are higher (Greenspan, Brown, & Edwards, 2016; Paley & O'Connor, 2009). In light of this barrier to service, research commonly refers to an IQ below 70 as a protective factor for individuals with FASD, as it allows access to specialized services, and can subsequently aid in lessening the occurrence of later adverse outcomes (Rasmussen et al., 2008; Streissguth et al., 2004).

1.1.5 Adverse outcomes. When individuals with FASD are unsupported entirely, or when interventions are not appropriately matched to their level of need, cognitive and behavioural difficulties can worsen and the risk for experiencing adverse life outcomes significantly increases (Streissguth et al., 2004). These outcomes are not a direct result of prenatal alcohol exposure but rather of the interaction between an individual's predisposed traits and an adverse environment (Clark et al., 2004). In other words, the direct consequences alcohol can have on the brain of an individual with FASD, such as executive function deficits, in combination with poor environmental factors, such as lack of a nurturing living situation, can together contribute to additional difficulties. Such outcomes can include, but are not limited to: mental health issues, disrupted school experiences, troubles with the law, incarceration, inappropriate sexual behaviour, as well as drug and alcohol problems (Clark et al., 2004; Petrenko, Tahir, Mahoney, & Chin, 2014; Popova et al., 2016).

Mental health concerns are argued to be the most prevalent adverse outcome, with research suggesting that up to 90% of individuals with FASD have a co-occurring mental health condition (Pei, Denys, Hughes, & Rasmussen, 2011; Streissguth et al., 2004). Mental health concerns often further complicate the everyday functioning of individuals with FASD and their ability to appropriately contribute and adapt to societal expectations (Pei, Tremblay, McNeil, Poole, & McFarlane, 2017; Pei et al., 2011; Rasmussen et al., 2008). The disorders most commonly diagnosed include Attention Deficit/Hyperactivity Disorder (ADHD), Anxiety disorders, Mood disorders, as well as Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD; McLennan, 2015; Pei et al., 2011; Weyrauch, Schwartz, Hart, Klug, & Burd, 2017). Individuals with FASD are also at an increased risk for suicidal ideation and suicidal attempts (O'Connor, Portnoff, Lebsack- Coleman, & Dipple, 2019; Pei et al., 2011). Recent findings support suicide attempts being five and a half times more likely among a sample of adolescents with FASD (13.0%) compared to a sample of age-matched youth (2.4%), while reported suicidal ideation was twice as high among the samples, respectively (O'Connor et al., 2019). Among children with prenatal alcohol exposure, mental health concerns have been shown to further lessen their capacity to control emotions, behaviours, and to interact pro-socially (Sandtorv, Hysing, Rognlid, Nilsen, & Elgen, 2017). Without appropriate identification and treatment, mental health concerns can have further repercussions on school success, peer relationships, the ability to take part in leisure activities, and can lead to issues with the law for individuals prenatally exposed to alcohol (Sandtorv et al., 2017).

As the aforementioned difficulties suggest, a differential diagnosis of FASD is important to allow individuals and families access to appropriate services and supports that can help them live manageable lives. An early diagnosis of FASD, commonly reported as before the age of 6,

can lessen adverse outcomes (Banerji & Shah, 2017; Streissguth et al., 2004), such as mental health concerns (Pei et al., 2011), and can reduce overall contact with the criminal justice system (Currie, Hoy, Legge, Temple, & Tahir, 2016). An early diagnosis of FASD can also aid in the transition to adulthood, and can help with the qualification for appropriate services and supports (Stade, Stevens, Ungar, Beyene, & Koren, 2006). Early diagnosis and participation in FASD targeted treatment have also been found to lessen caregiver distress (Zarnegar, Hambrick, Perry, Azen, & Peterson, 2016), with specific research demonstrating this need in Northern Ontario (Watson, Hayes, Coons, et al., 2013). While families have reported that various challenges exist in the diagnostic process, they have also explained that obtaining a diagnosis was pivotal in getting their child the appropriate help and understanding of their concerns (Watson, Hayes, Coons, et al., 2013).

1.2 How FASD is Diagnosed in Canada

Currently, to be considered for a diagnosis of FASD in Canada, the recently revised diagnostic guidelines require both an extensive medical and neurodevelopmental assessment (Cook et al., 2016). Assessments are completed by a multidisciplinary team that consists of a paediatrician or physician, psychologist, speech and language pathologist, and occupational therapist to accurately examine the individual's level of function. Confirmation of prenatal alcohol exposure must also be made by means of a reliable source, such as through clinical observation or self-report by the biological mother herself. Together, the confirmation of prenatal alcohol exposure and evidence of severe impairment (greater than or equal to 2 SD below the mean) in three of the ten neurodevelopmental domains (including, motor skills, neuroanatomy, cognition, language, memory, attention, academic achievement, executive functioning, affect regulation and adaptive behaviour, social skills or social communication), specify a diagnosis of

“FASD without sentinel facial features”. The diagnosis of “FASD with sentinel facial features” is given when the individual presents with all three sentinel facial features, there is evidence of impairment in three of the ten neurodevelopmental domains, and prenatal alcohol exposure is either confirmed or unknown.

Added in the recent revision of the Canadian Diagnostic Guidelines, individuals who fall just below the threshold for a diagnosis can be given the designation of at risk for the development of FASD (Cook et al., 2016). For individuals who meet this criteria, prenatal alcohol exposure is confirmed and there is an indication of neurodevelopmental impairment; however, assessment results failed to meet criteria but for a reasonable explanation (i.e., individual was too young, incomplete assessment). Prior to these guidelines implemented in 2015, there have been several other guidelines that are still used by some medical professionals today. These systems include the Institute of Medicine (IOM) Descriptions (Stratton, Howe, & Battaglia, 1996), The 4 Digit Diagnostic Code (Astley & Clarren, 1999; Astley & Clarren, 2000), and the previous Canadian Diagnostic Guidelines (Chudley et al., 2005). However, in Canada, most diagnostic clinics have adopted and are found to follow the recently published guidelines (Coons-Harding et al., 2019).

1.2.1 Diagnostic process in Sudbury Ontario. Sudbury, Ontario has an FASD Diagnostic Clinic that services children and youth 18 years of age and younger across Northeastern Ontario. Their multidisciplinary team includes a social worker, nurse practitioner, psychologist, occupational therapist, and a speech language pathologist, who together assess various aspects of a child’s functioning in line with the Canadian FASD Diagnostic Guidelines (i.e., 10 neurodevelopmental domains; assessed using standardized measures outlined in Appendix B). This process is typically completed over a three-day duration at the Northeastern

Ontario Kids Pediatric Clinic (NEO Kids), which is located at Health Sciences North in Sudbury. After completion of the assessment process, the diagnostic team meets and reviews the patient's history, as well as observational and assessment findings to decipher whether they meet diagnostic criteria for an FASD related diagnosis. Families are subsequently debriefed, and recommendations and connections to services are provided where deemed appropriate.

1.3 Purpose

As part of a larger study that provides unique insight into the profile of Canadians assessed for FASD, the purpose of the current study was to highlight the diagnostic outcomes and support needs of individuals with prenatal alcohol exposure in Northeastern Ontario. To the author's knowledge, no previous studies have examined diagnostic outcomes for FASD in Northeastern Ontario, while also using a comprehensive and universal database. Using the National FASD Database in the current study allowed for a descriptive profile of individuals assessed for FASD in Northeastern Ontario to be established, as well as for individuals who received an FASD diagnosis and those who did not to be compared. The breadth of information gathered is together useful in informing service and resource needs for this population in the region.

1.3.1 Research questions. The current study is exploratory and seeks to answer the following questions:

- 1) What is the diagnostic profile of individuals who present for an FASD assessment in Northeastern Ontario?
- 2) How does the profile of individuals diagnosed with FASD (with and without sentinel facial features) compare with those of individuals who do not receive an FASD diagnosis, as well as those given an at risk designation?

3) What are the average IQ scores of children and youth diagnosed with FASD in the sample?

3a) What proportion of individuals with FASD presented with an Intellectual Disability?

3b) Does IQ account for deficits in adaptive behaviour among individuals with FASD?

3c) Do the rates of adverse outcomes among individuals with FASD differ according to their IQ and age?

1.4 Methodology

As part of the larger research project in collaboration with the CanFASD National FASD Database project, diagnostic files of individuals assessed for FASD at the Sudbury FASD Diagnostic Clinic in Northeastern Ontario were retrospectively reviewed. For each individual, information collected at the time of their referral and upon completion of the FASD diagnostic assessment was reviewed and transferred to an online questionnaire (i.e., the National FASD Database) through the secure web forum, Redcap, hosted at the University of Alberta. The National FASD Database includes a wide variety of questions, comprising information related to demographics, referral, presenting concerns, medical health history, mental health, FASD diagnosis, impaired neurodevelopmental domains, current issues being experienced, other factors, and recommendations for services and supports. Questions were either answered by clicking a box indicating whether or not the client endorsed an item, or typed into a designated textbox. Please refer to Appendix A for a copy of the “Database”.

For the current study, specific items in the National FASD Database were used to create a profile of individuals assessed for FASD at the Sudbury FASD Diagnostic Clinic. Individuals were then grouped based on their diagnosis (i.e., FASD or No FASD) and compared using

several database items. The National FASD Database items that were used in the current study included:

- Referral source (e.g., social services)
- Ethnicity and Gender
- Current living situation (e.g., foster care)
- Reasons for Referral (e.g., behavioural concerns, social skills difficulties)
- Impaired neurodevelopmental domains (e.g., motor skills, neuroanatomy, cognition, language, memory, attention, academic achievement, executive functioning, affect regulation, and adaptive behaviour, social skills or social communication)
- Intelligence Quotient (IQ) scores
- Current issues being experienced (e.g., requires a teacher's assistant)
- Co-occurring mental health conditions (e.g., attachment disorder)
- Other factors (e.g., trauma)

The overall descriptive profile was determined based on the degree of endorsement (i.e., using frequency counts) among all children and youth in the sample on the previously identified questions from the Database, as well as through the use of descriptives (i.e., measures of central tendency). Individuals who received an FASD diagnosis and individuals who did not were then compared based on specific Database questions to look for group similarities, or differences, as these could potentially speak to differing strengths, difficulties, and needs.

Ethics approval for the larger National FASD Database project was obtained by the principal investigators through the Ottawa Health Science Network Research Ethics Board. An ethics application for the current study was submitted and approved by the Laurentian University

Research Ethics Board, approval number 60149B4 (see Appendix C). A separate application completed by the principal investigator of the current study was sent to the Canada FASD Research Network and principal investigators of the larger study to obtain access and use of the secondary data for the purpose of the current study.

1.4.1 Participants. In total, 326 children and youth assessed for FASD at the Sudbury FASD Diagnostic Clinic were included in this study. The sample consisted of 203 males (62.3%) and 123 females (37.7%). Individuals ranged between 1 and 17 years of age, with a mean age of 10.24 (SD = 3.83). The sample consisted of more individuals who did not receive a diagnosis of FASD (50.9%) compared to those who did receive a diagnosis of FASD (38.7%), and those given an at risk designation (10.4%). Individuals who received an at risk designation were excluded from the group comparisons given the nature of the diagnosis and the amount of missing and incomplete data that was present in these cases. Table 1 below shows the demographic details of the participant population in this study.

Table 1

Participant Demographic Characteristics

Demographic Characteristics	
Gender	
Male <i>n</i> (%)	203 (62.3)
Female <i>n</i> (%)	123 (37.7)
Average age (SD)	
Age range	10.24 (3.83) 1 - 17
Ethnicity	
Caucasian <i>n</i> (%)	122 (37.4)
Indigenous <i>n</i> (%)	204 (62.6)
Diagnosis	
FASD	126 (38.7)
No FASD	166 (50.9)
At Risk	34 (10.4)

1.5 Conclusion and Overview of Subsequent Chapters

The current study, which employed a retrospective chart review and secondary data analysis of children and youth assessed for FASD in Northeastern Ontario, aimed to provide information, for the first time, on individuals with prenatal alcohol exposure in Northeastern Ontario, from a diagnostic perspective. While the larger National FASD Database project collects a wide range of information, the current study focused on information related to the individual's referral, including difficulties and presenting concerns, as well as assessment and diagnostic outcomes. The specific Database items were chosen in an effort to answer the current study's research questions in the most effective and meaningful way. The nature of the information collected also speaks directly to the types of support individuals with prenatal alcohol exposure and their families require, given their presenting needs, as well as the current demands for services and supports that exist within Northeastern Ontario.

The first paper provides a descriptive overview and profile of the full sample of individuals who were assessed for FASD in the Northeastern region. Within this paper diagnostic outcomes between individuals diagnosed with FASD and those who did not receive a diagnosis are also compared. Findings indicate that while differences did exist between groups, whether a diagnosis was provided or not, individuals were experiencing significant difficulties and impairments that warrant a range of supports and interventions. The second paper examines the intelligence quotient (IQ) scores among this sample of children and youth diagnosed with FASD and the relationship between IQ, adaptive behaviour impairment, and adverse outcomes. This paper further explores individuals' age and rates of adverse outcomes. Results reveal that IQ was unrelated to the rates of adaptive behaviour impairment and adverse outcomes, while age was

significantly related to the rates of adverse outcomes among this sample of children and youth with FASD.

Following these two papers, the final chapter provides a summary of the findings in each paper, outlines areas for future research, and discusses various clinical and practical implications.

Fetal Alcohol Spectrum Disorder in Northeastern Ontario: A Descriptive Examination of
Who is Assessed, Who Receives a Diagnosis, and Who Does Not

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Abstract

As part of a larger project that provides unique insight into the profile of Canadians assessed for Fetal Alcohol Spectrum Disorder (FASD) across various diagnostic clinics, the purpose of this paper is to highlight who presents for FASD assessment in Northeastern Ontario, and the related diagnostic outcomes. A total of 326 children and youth were included in the overall sample of individuals assessed at the only diagnostic service in the Northeastern Ontario region in Sudbury, Ontario. Results indicate that functional difficulties, including both neurodevelopmental and mental health impairments, were evident in all participants, regardless of an FASD diagnosis. However, for individuals who received a diagnosis of FASD, greater mental health concerns and neurodevelopmental impairment beyond what is necessary to receive a diagnosis were noted. While impairment at the clinical level (i.e., 2 or more SD below the mean, as per Canadian FASD Diagnostic Guidelines) was lower in those who did not receive a diagnosis, difficulties pertaining to behaviour and mental health were noted. Overall results support a multiservice need among those prenatally exposed to alcohol in the region. Findings are further discussed in relation to the existing literature on the common outcomes associated with prenatal alcohol exposure, and FASD more specifically. Limitations and implications are also discussed.

Keywords:

Fetal alcohol spectrum disorder, prenatal alcohol exposure, Northeastern Ontario, assessment, diagnosis.

**Fetal Alcohol Spectrum Disorder in Northeastern Ontario:
A Descriptive Examination of Who is Assessed, Who Receives a Diagnosis, and Who
Does Not**

While there is a growing body of research on the typical patterns of deficits and common challenges associated with Fetal Alcohol Spectrum Disorder (FASD), little research has examined diagnostic outcomes in a Canadian sample, and no research has considered them in Northeastern Ontario. A study conducted in Northern Ontario examining parenting stress among families of children with FASD identified a significant need for services, specialized supports, and public knowledge surrounding the disorder (Watson, Hayes, Coons, & Radford-Paz, 2013). Furthermore, a 2015 Northern Policy Institute report revealed that individuals living in Northern Ontario face specific challenges in terms of accessing health care services, a lack of culturally appropriate care, as well as increased mental health concerns, as a result of both geographical and economic disparities (Al-Hamad & O’Gorman, 2015). These challenges, along with the established difficulties individuals with FASD and their families face, as well as a lack of research for FASD in Northeastern Ontario, suggests the need for attention in this area. The aim of the current study was to examine diagnostic outcomes of individuals assessed for FASD in Northeastern Ontario, while addressing how to best support persons prenatally exposed to alcohol in the region, through targeted services, supports, and interventions.

Common Outcomes Associated with FASD and Prenatal Alcohol Exposure

A consistent finding throughout the FASD literature is that the emotional, social, and familial impacts of FASD are profound (Popova, Lange, Burd, & Rehm, 2015; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008; Watson, Hayes, Coons et al., 2013). At the individual level, both cognitive and behavioural impairments have been shown to significantly impede the

success, fulfillment, and general well-being of those with FASD (Rasmussen et al., 2008; Stade, Stevens, Ungar, Beyene, & Koren, 2006). Most notably, structural damage caused by prenatal alcohol exposure, which often impairs essential areas of an individual's brain severely compromises an individual's capacity to effectively plan and control behaviour (Mattson, Crocker, & Nguyen, 2011; Rasmussen, Soleimani, & Pei, 2011). Consequently, abilities such as decision making, organizing, inhibition, and the use of working memory can be difficult and in some cases unmanageable for individuals with FASD (Rasmussen et al., 2008). Other areas of difficulty often include academic achievement, learning, language, social communication, memory, attention, and intellectual functioning (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009; Mattson et al., 2011; Rasmussen, Horne, & Witol, 2006; Streissguth, Barr, Sampson, & Bookstein, 1994). Deficits in executive and adaptive skill functioning in individuals with FASD are particularly problematic and have been shown to have significant repercussions on skills in daily living (e.g., personal hygiene), socialization (e.g., the ability to cooperate with others), and communication (e.g., the ability to understand and use words; Paley & O'Connor, 2009; Streissguth et al., 2004).

Individuals with FASD have impairment in several neuropsychological areas, with the specific areas of deficit being unique to each individual, and thus creating variation in the presentation of the disorder (Carr, Agnihotri, & Keightley, 2010; Chudley, 2008). Mental health conditions commonly also co-exist within this population and further complicate the individual's everyday functioning and potential treatment (Pei, Denys, Hughes, & Rasmussen, 2011; Popova et al., 2016). Considering the wide-spread impairment, individuals with FASD require comprehensive and consistent support and guidance throughout their lives to provide them with direction, advice, structure, and to aid in their decision making (Coons, 2013; Streissguth et al.,

1994). Families often fulfill this mediating role, and have been found to experience significant and unique stress related to worry, daily demands, and the lack of understanding and awareness of their family member's difficulties (Michaud & Temple, 2013; Watson, Hayes, Coons et al., 2013).

Research has shown that individuals prenatally exposed to alcohol who do not meet diagnostic criteria for FASD may still experience difficulties similar to those who are diagnosed (Kodituwakku, Kalberg, & May, 2001; Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012; Sood et al., 2001). One meta-analysis examining differences in behaviour outcomes between children with prenatal alcohol exposure and those diagnosed with FASD found that prenatal alcohol exposure alone was associated with poor behaviour ratings (Tsang, Lucas, Olson, Pinto, & Elliott, 2016). Likewise, other studies have demonstrated that compared to controls, children and youth with prenatal alcohol exposure had lowered general intelligence (Mattson et al., 2011), executive functioning deficits (McGee, Fryer, Bjorkquist, Mattson, & Riley, 2008), difficulties with learning and memory (Mattson & Roebuck, 2002), as well as increased rates of psychopathology (Mattson & Riley, 2000). Together, these findings highlight the importance of addressing the particular areas of service need and their availability for individuals prenatally exposed to alcohol who do not meet diagnostic criteria, but who present with difficulties.

FASD in Northeastern Ontario

Though the prevalence of FASD in Northeastern Ontario is largely unknown, past research has reported increased rates in communities with a similar geography to Northeastern Ontario (Tough, Ediger, Hicks, & Clarke, 2008). It has also been found that health care providers

practicing in rural parts of Ontario report greater exposure to patients with FASD compared to those practicing in urban locations (Coons, Clement, & Watson, 2017).

In 2011, the first ever FASD diagnostic clinic in Northeastern Ontario was established in Sudbury, Ontario, which services children and youth under the age of 18. Prior to the clinic's establishment, families often had to travel long distance or teleconference with health professionals to access an FASD diagnosis (Watson, Hayes, Coons, et al., 2013). As of March 2020, 255 individuals were on the waitlist to be assessed at the Sudbury Clinic and the average wait time was estimated to be between 12 to 18 months. The Sudbury FASD multidisciplinary team assesses each individual in line with the Canadian FASD Diagnostic Guidelines (Cook et al., 2016) and provides referrals to available services and supports in the region when appropriate. A unique aspect of the Sudbury FASD Diagnostic Clinic is that confirmation of prenatal alcohol exposure is confirmed by means of a reliable source for each referral prior to FASD assessment. This protocol allows for greater certainty that the deficits and difficulties individuals present with, and thus those depicted in the current study, are a result of prenatal alcohol exposure.

Methods

The current study is part of a Canada wide project examining the patterns of difficulties, challenges, and needs of individuals assessed for FASD in Canada. In collaboration with the Canada FASD Research Network (CanFASD) National Database project, a retrospective chart review and secondary data analysis of children and youth who have been assessed for FASD at the Sudbury FASD Diagnostic Clinic in Northeastern Ontario was conducted. For each individual, diagnostic information collected at the time of referral, as well as upon completion of the FASD diagnostic assessment, was transferred to the online National FASD Database through

the secure web base format RedCap. After all accessible charts were reviewed and Database records were submitted, a request for data from specific database items was sent by the principal investigator of this study to CanFASD to permit access to the Northeastern Ontario data.

Requested Database items provided information on demographics, referral reasons including presenting issues and concerns, as well as assessment and diagnostic outcomes. Ethical approval for the current study was obtained through the Laurentian University Ethics Board, Ontario, Canada, which follows Tri-Council recommendations for Research with Human Participants.

Participants. A total of 326 children and youth assessed for FASD at the Sudbury FASD Diagnostic clinic were included in the descriptive profile of the Northeastern Ontario population who presented for an FASD assessment. A total of 34 individuals were then removed from the sample due to missing or incomplete data, and the remaining 292 children and youth were grouped by their diagnosis (i.e., FASD or No FASD) and were compared. A full summary of the total sample demographics, compared by diagnosis, is displayed in Table 1.

Data analysis. Data were analyzed using Statistical Package for the Social Sciences (SPSS) edition 24. Descriptive analyses were run to create a profile of who was assessed for FASD in Northeastern Ontario using all National FASD Database items requested. Chi-square analyses and independent samples *t*-tests were then performed to examine differences in diagnostic outcomes between those diagnosed with FASD and those who did not receive a diagnosis.

Results

Who Presented for FASD Assessment in Northeastern Ontario

Of the total number of children and youth ($N = 326$) included in the current study, 62.6% were Indigenous, while 37.7% were Caucasian. A greater number of males (62.3%) were assessed than females (37.7%), with the average age of individuals being 10.24 ($SD = 3.83$). A large proportion of children and youth were referred for an FASD assessment because of behavioural concerns (e.g., physical aggression; 84.7%), followed by difficulties with learning (48.2%), as well as social skills difficulties (47.9%). Individuals were referred for an FASD assessment mainly from social service agencies (41.4%), medical professionals (34.0%), or a family member (19.6%), while the education system was identified as a referral source in 2.5% of cases among this sample of children and youth. When examining participants' current living situations, 25.2% were living in foster care, 23.9% were adopted, 23.9% lived with other family members, and 22.7% lived with their biological parent(s).

More than half of the individuals in the sample had reported trauma (e.g., documented neglect, physical or sexual abuse; 62.3%). The number of reported mental health concerns (e.g., diagnoses listed in Table 2) in the sample varied ($N = 326$; 0 – 7), with individuals presenting, on average, with 1 ($SD = 1.5$) mental health concern. Within this overall sample, 27.3% of children and youth had one reported mental health concern, 37.8% had two or more reported mental health concerns, and 33.4% had no identified mental health concerns. In 1.5% of cases information regarding mental health concerns was not reported. Attention Deficit Hyperactivity Disorder (ADHD) was the most commonly reported mental health concern (52.1%), followed by Oppositional Defiant Disorder (ODD; 15.3%), and Intellectual Disability (14.7%). Suicide ideation/attempt was also reported in 15.3% of the sample. When examining areas of

neurodevelopmental impairment, as per the Canadian FASD Diagnostic Guidelines, individuals on average were significantly impaired in two neurodevelopmental domains. Areas most commonly impaired included, language, academic achievement, and cognition. The full demographic profile of individuals who were assessed for FASD in Northeastern Ontario is displayed in Table 2.

Demographic and Referral Differences

Chi-square analyses were performed to examine demographic differences between individuals who received a diagnosis of FASD and those who did not. Individuals with FASD did not differ from individuals without FASD by ethnicity or gender ($p_s > .05$). However, results of an independent samples t -test revealed a statistically significant difference between groups for age, $t(290) = 2.565, p = .011$. Individuals who received an FASD diagnosis ($M = 11.29, SD = 3.61$) were older than those who did not receive a diagnosis ($M = 10.16, SD = 3.77$). When comparing individuals' current living situation, no significant differences were found between groups ($p > .05$). A closer examination revealed that individuals with FASD and individuals without FASD were similarly living in foster care (FASD: 25.4%, No FASD: 27.7%), with adoptive families (FASD: 25.4%, No FASD: 22.9%), with biological parents (FASD: 25.4%, FASD: 19.9%), or with other family members (FASD: 18.3%. No FASD: 25.3%).

A separate chi-square analysis was performed to determine whether groups differed based on the source of referral, and results revealed no significant differences ($p > .05$). Additional chi-square analyses were run to determine if groups differed by reasons for referral (e.g., behavioural concerns). The results indicated that a significantly greater proportion of individuals with FASD (64.3%) were referred for learning difficulties compared to those with No

FASD (38.6%) [$\chi^2(1, n = 292) = 18.97, p < .001$]. Individuals diagnosed with FASD (17.5%) were also more likely to be referred for developmental delays compared to individuals with No FASD (7.8%) [$\chi^2(1, n = 292) = 6.29, p = .012$]. In contrast, significantly more individuals without FASD (54.2%) were referred because of social skills difficulties than individuals with FASD (41.3%) [$\chi^2(1, n = 292) = 4.80, p = .028$]. Groups did not significantly differ (all $p_s > .05$) for all other referral reasons, which are outlined in Table 2.

Mental Health Differences

An independent samples *t*-test was run to determine whether a difference existed in the total number of co-occurring mental health diagnoses between individuals with FASD and those without FASD. Results revealed a statistically significant difference between groups, $t(287) = 4.884, p = .028$, indicating that individuals diagnosed with FASD ($M = 2.00, SD = 1.62, \text{range } 0 - 7$) had a greater number of mental health concerns than those without FASD ($M = 1.11, SD = 1.37, \text{range } 0 - 6$). Of the children and youth diagnosed with FASD ($n = 126$), 15.9% had no reported mental health concerns, 31.7% had one reported mental health concern, 17.5% had two reported concerns, and 33.4% had three or more reported mental health concerns. In 1.5% of cases information on mental health concerns was not reported. Among the children and youth not diagnosed with FASD ($n = 166$), 44.6% had no reported mental health concerns, 25.3% had one mental health concern, while 29.5% had two or more reported mental health concerns. In .6% of cases information regarding mental health concerns was not reported.

Chi-square analyses were then performed to examine differences between individuals with FASD and individuals without FASD for specific mental health concerns. Individuals with FASD (15.1%) made up a significantly greater proportion of those diagnosed with Conduct

Disorder (CD) compared to their counterparts (1.8%) [$\chi^2 (1, n = 45) = 4.87, p = .027$].

Conversely, a statistically significant result was also found for ODD [$\chi^2 (1, n = 48) = 5.61, p = .018$], indicating that more individuals without FASD (16.3%) had a diagnosis of ODD compared to individuals with FASD (13.5%). In an effort to further explore whether these diagnoses differed by the gender or age of the children and youth in the sample, separate chi-square analyses were performed. Results indicated no significant differences between age and gender for both the diagnosis of CD and ODD (all $p_s > .05$).

A statistically significant finding was reported between diagnostic groups for suicidal ideation and or attempt [$\chi^2 (1, n = 106) = 7.16, p = .007$]. Results revealed that a greater number of individuals diagnosed with FASD (23.0%) had past suicidal ideation or a suicide attempt compared to individuals with No FASD (12.7%). Findings also show that significantly more individuals without FASD (6.6%) had a comorbid diagnosis of Post Traumatic Stress Disorder (PTSD) than individuals with FASD (4.8%) [$\chi^2 (1, n = 22) = 6.47, p = .011$]. Additional analyses revealed no significant differences (all $p_s > .05$) between groups for all other mental health concerns. A summary of these mental health findings is reported in Table 2, with the respective sample sizes.

Other Factors

A chi-square analyses was run to determine whether individuals diagnosed with FASD compared to individuals with No FASD differed on the rate of reported trauma (e.g., reported neglect and or abuse). Results revealed no significant difference between the groups (FASD: 66.7%, No FASD: 62.0%).

Differences in Impairment Across Neurodevelopmental Domains

The total number of impaired neurodevelopmental domains between groups was compared using an independent samples *t*-test, and a significant result was found, $t(289) = 50.15$, $p < .001$. Findings indicated that individuals who received a diagnosis of FASD ($M = 4.53$, $SD = 1.53$) had a greater degree of neurodevelopmental impairment compared to those with No FASD ($M = .78$, $SD = .78$). Of the children and youth diagnosed with FASD ($n = 126$), 27.8% were significantly impaired in up to three neurodevelopmental domains, and 71.4% were impaired in four or more domains. Among those not diagnosed ($n = 166$), 43.4% had no significant neurodevelopmental impairment, 34.9% were significantly impaired in one neurodevelopmental domain, and 21.7% had significant impairment in two domains. Table 3 summarizes the findings of separate chi-square analyses comparing individuals with FASD and their counterparts for each of the 10 neurodevelopmental domains included in the Canadian FASD Diagnostic Guidelines.

Discussion

The overall findings of the current study convey that regardless of an FASD related diagnosis, children and youth with prenatal alcohol exposure in Northeastern Ontario presented with a variety of functional difficulties and challenges. Likewise, for several of the diagnostic outcomes, no significant differences were reported between groups, which supports the need to consider participants who did not meet diagnostic criteria. While results for the overall sample as well as group comparisons were reported, only main findings for each diagnostic outcome will be discussed.

Demographic Findings

The overall demographic findings speak to the unique population that accesses the FASD diagnostic service in Northeastern Ontario, and demonstrates the importance of accessible and culturally appropriate supports in the region. For instance, the location in which the Sudbury FASD Diagnostic Clinic is located is home to more than 300,000 Indigenous Peoples, and encompasses over 150 First Nations communities (Statistics Canada, 2016), which is evidenced in the current study by the proportion of Indigenous participants. It has been argued that effective prevention and management interventions for FASD in Indigenous communities requires the adaptation of services and resources to include culturally relevant and meaningful components (Banerji & Shah, 2017).

A search conducted through FASD Ontario identified 11 current service and support options in the Northeastern region that are Indigenous specific (FASD Ontario, 2019). A closer examination revealed that a wide variety of support is offered from these services, including one-to-one support, traditional supports, cultural awareness workshops, nutrition workshops, mental health supports, and system navigation assistance for Indigenous families (FASD Ontario, 2019). Notably, together these services offer support to individuals from infancy to adulthood, and for several of the listed services a diagnosis of FASD was reportedly not required. An important finding in the current study was that the diagnosis of FASD was applied at a rate that was not significantly different between the Indigenous and Caucasian participants. This finding serves to further dismantle the myth that FASD is a disorder that exclusively exists within Indigenous communities (Flannigan, Unsworth, & Harding, 2018) and suggests that similar challenges with respect to FASD are experienced by different groups of people. As such, our findings support the

need for services and supports to be similarly available and accessible to all persons living within the region.

Participants' living situation also helps speak to where FASD services in Northeastern Ontario are needed and to whom they should be accessible. The majority of the children and youth who presented for an FASD assessment were in foster placements or had been adopted. Previous Canadian research has suggested that children with prenatal alcohol exposure are more likely to come into contact with the foster care system, and to experience multiple placements once involved with this system (Popova, Lange, Burd, & Rehm, 2014). While the number of placements for participants in the current sample is unknown, behavioural challenges, which are evident in this study, are an established precursor to placement breakdowns (Fuchs, Burnside, Marchenski, & Mudry, 2008). Thus, our findings support an increased need for specialized services, supports, and resources for foster and adoptive families caring for a child prenatally exposed to alcohol in Northeastern Ontario in an effort to keep placements stable. This can be seen as particularly relevant as frequent changes in one's living environment for individuals with FASD has been identified as a significant risk factor for many adverse life outcomes (Streissguth et al., 2004) as well as poorer cognitive and behavioural functioning (Victor, Wozniak, & Chang, 2008).

The average age at which participants in the sample accessed the diagnostic service lends additional support to the lack of education and awareness towards the disorder among community members in the region (Watson, Hayes, Coons et al., 2013). Previous literature has suggested that little knowledge towards the consequences of prenatal alcohol exposure and the common manifestations of FASD makes for the timely identification and subsequent diagnosing of the disorder extremely delayed or missed altogether (Chudley, 2008; Paley & O'Connor,

2011). Beyond educating the general public of these implications, the current study also identifies the need to inform school educators in the region. Not only had participants' on average been in school for approximately 6 years before being assessed, but less than 3% of referrals in the entire sample were made by schools. This information as well as the proportion of children and youth reported to have learning difficulties in our sample (48.7%) suggests that not only are students with prenatal alcohol exposure in the region struggling in school, educators may not be appropriately identifying concerns and supporting their learning needs.

Referral Source Findings

The finding that the majority of participants in the current study were referred for FASD assessment by social service agencies is not surprising given the proportion of participants living in either foster or adoptive care. Therefore, it is possible that concerns regarding the atypical development and behaviours of children with FASD are acknowledged and acted upon more frequently by foster and adoptive families. For example, past research has found that non-biological families who are often unaware of the child's prenatal alcohol exposure are likely to seek multiple health care services in an attempt to better understand their child's challenges (Rowbottom, Merali, & Pei, 2010).

Furthermore, while almost half of the participants in the current study were living with either their biological parent(s) or with other family members, less than 20% of referrals were made by families. This finding potentially speaks to an additional need for community prevention and educational approaches in an effort strengthen referrals from these sources. Drawing upon recent research on effective FASD prevention and education methods, sharing the diagnostic information collected in the current study through the use of non-stigmatizing,

community-based educational programming or in direct work with women of child-bearing age and their families (Choate, Badry, MacLaurin, Ariyo, & Sobhani, 2019) may be beneficial.

Results of the current study also show that medical professionals in the region are playing an active role in the referral process. Contrary to this finding, past research identified a lack of exposure and education for FASD among Northern Ontario medical school students (Coons, Watson, Yantzi, Lightfoot, & Larocque, 2017), as well as a heavy reliance on non-reliable sources for FASD education by medical professionals practicing in rural locations in Ontario (Coons et al., 2017). Although our findings seem promising, results also indicate that medical professionals, along with the other referral sources, referred individuals who received a diagnosis of FASD and those who did not at a similar rate. Given the expected level of expertise for medical professionals, these findings therefore indicate a need for them to receive ongoing, specialized education regarding FASD to aid in a greater number of valid referrals, as well as for better screening and recognition of symptoms of FASD.

Reasons for Referral Findings

When considering the reasons participants were referred for an FASD assessment, a significant number of individuals were experiencing behavioural concerns (84.7%). Problematic behaviour is a common concern among this population, with a separate study of children and youth reporting them in 90% of their sample (Reid, Shelton, Warner, Callaghan, & Dawe, 2017). While the exact behavioural difficulties of participants could not be ascertained using the National FASD Database, in keeping with past research, externalizing and aggressive behaviours, as well as maladaptive behaviours, such as lying and stealing, are reported as particularly challenging (Rasmussen et al., 2008; Watson, Hayes, Coons, et al., 2013). The

degree of problematic behaviours in the current study can be further supported by the proportion of individuals who were removed from school, had difficulties with the law, and those reported to have been offenders. Concerningly, poor behavioural outcomes have been found to persist and intensify with age for individuals with prenatal alcohol exposure (Spohr, Willms, & Steinhausen, 2007), thus highlighting the importance of intervention. In saying this, it is important to note that few behavioural interventions that appropriately address the multifaceted nature of FASD, targeting both primary and secondary impacts exist (Paley & O'Connor, 2011).

Apart from the behavioural difficulties affecting all participants similarly, findings indicate that individuals with FASD were more likely to be referred for learning difficulties. It has been argued that for individuals with FASD, deficits in areas such as attention, executive functioning, and memory, which together interact to foster effective learning, commonly interfere with one's academic achievement (Millians, 2015). Additional research has suggested that language deficits may limit one's ability to follow classroom directions and discussions, which can have additional implications on learning (Clarke & Gibbard, 2003). Past research has found that teachers report difficulties in understanding diagnostic evaluations for students with FASD, that reports lack school-specific information and strategies, and that in-service trainings for FASD fail to address the specific challenges and needs that may arise in the classroom (Pei, Job, Poth, & Atkinson, 2013; Ryan & Ferguson, 2006). Thus, ongoing, relevant, and appropriate training for educators may be especially useful, as it has also been found that teachers who report having more experience on the job also report being able to work with students with FASD more effectively (Ryan & Ferguson, 2006).

Additionally, a greater number of individuals in the sample who did not receive a diagnosis of FASD were referred because of social skills difficulties compared to those who

were diagnosed. In saying this, a wealth of literature exists which associates prenatal alcohol exposure at varying levels of clinical impairment with social skill difficulties (Kully-Martens et al., 2011; McGee, Bjorkquist, Price, Mattson, & Riley, 2009; McGee et al., 2008). Although specific difficulties are not known in this study, previous research identifies understanding social cues, communicating in social contexts, and processing social information as areas of frequent concern (Greenbaum et al., 2009; McGee et al., 2008; McGee et al., 2009). It is important to address social skill deficits as they have been associated with social rejection, and can contribute to difficulties with self-esteem, aggression, mental health issues, and can negatively impact a child's social development (Kully-Martens et al., 2011; Paley & O'Connor, 2011).

Mental Health

Mental health concerns were present among both groups of participants, though a greater number of co-occurring diagnoses were reported among individuals with FASD compared to those without FASD. Consequently, our findings support significant rates of mental health outcomes in children and youth with FASD, with 82.5% of our sample with FASD having presented with mental health concerns. Overall, ADHD was the most frequently reported mental health concern among both groups, a finding which is reflected throughout the literature (Fryer, McGee, Matt, Riley, & Mattson, 2007; Pei et al., 2011). When considering the current study's findings, it is important to highlight the significant overlap in symptoms between FASD and ADHD (Rasmussen et al., 2010), which has been argued to lead to the potential misdiagnosing of disorders (Graham et al., 2013). That said, when ADHD is diagnosed in individuals with FASD, researchers have noted a unique presentation that is characterized by an earlier onset, primarily the inattention subtype, with various developmental, psychiatric, and medical comorbidities (O'Malley & Nanson, 2002). The presence of both FASD and ADHD has also been associated

with greater and more severe behavioural symptoms compared to alcohol exposure without ADHD (Ware et al., 2013). Together, these findings help stress the importance of accurate diagnosing to ensure appropriate treatment, while supporting the argument that effective management of ADHD symptoms in those prenatally exposed to alcohol requires a tailored treatment approach (O'Malley & Nanson, 2002).

When considering other externalizing disorders, a greater proportion of participants without FASD had a diagnosis of ODD, while more individuals with FASD presented with a diagnosis of CD. Consistent with the literature, both ODD and CD are described as common outcomes of prenatal alcohol exposure (Brown et al., 2018; Easey, Dyer, Timpson, & Munafo, 2019; Nash, Koren, & Rovet, 2011). Taking into account the potential implications on the individual, both diagnoses indicate significant disruptions in mood and behaviour, with behaviours being of a more severe nature in CD (American Psychiatric Association [APA], 2013). These findings make sense in light of the behavioural concerns evident in the overall sample. The finding that CD was reported more in individuals diagnosed with FASD can be supported by research connecting neurocognitive deficits, specifically executive functioning impairments, with an increased vulnerability of engagement in high risk and criminal behaviours typical of CD (Wyper & Pei, 2016). Though FASD and CD share many of the same features, such as a lack of social judgement and impaired cause and effect reasoning, the presence of both disorders has been shown to further increase one's vulnerability to high risk behaviours and the severity of these outcomes (Wyper & Pei, 2016). Considering the combined implications of FASD and CD suggests that the timely and accurate recognition, diagnosis, and intervention of ODD among individuals with prenatal alcohol exposure is crucial, as it is an established potential precursor to the development of CD in both general and clinical populations (APA, 2013).

An important mental health finding was that a significantly greater proportion of individuals with FASD had a reported attempted suicide and or suicidal ideation compared to those not diagnosed. Previous researchers have suggested that neuropsychological, mental health, and environmental factors that are often present in individuals with FASD elevates their risk for suicidal thoughts and behaviours (Wyper & Pei, 2016). For instance, in one study with a similar age demographic to the current study, suicide attempts were prevalent in 3% of children and 12% in youth (Huggins, Grant, & Streissguth, 2008). In a more recent study, suicidal ideation was reported in 32.5% of adolescents with FASD with 13% having required medical intervention after making a serious suicide attempt (O'Connor, Portnoff, Lebsack-Coleman, & Dipple, 2019). Notably, among adolescents with FASD psychosocial stressors such as the number of living placements, as well as comorbid mental health conditions, both identified factors in the current study, were risk factors for suicidal ideation (O'Connor et al., 2019).

While the modification of risk factors for suicide can in turn be protective and are commonly targeted as part of suicide prevention, some factors may be difficult if not impossible to change for individuals with prenatal alcohol exposure (Huggins et al., 2008). For example, one's living environment may not be modifiable, while instilling skills such as positive coping and effective problem solving may be difficult as a result of cognitive deficits (Huggins et al., 2008). Likewise, it has been argued that suicide risk assessments among this population and subsequent interventions ought to be modified based on individual needs (Jonsson, Dennett, & Littlejohn, 2010). More specifically, memory, language, and reasoning deficits may require the use of concrete terms and consistent checking of understanding when assessing suicidal risk (Huggins et al., 2008). Furthermore, a structured, problem-focused approach that teaches skills

and uses close-ended questions in a multimodal form may be most effective in terms of intervention (Huggins et al., 2008).

Other Factors

A large proportion of participants in the current study had a reported history of trauma, including but not limited to neglect, as well as sexual and physical abuse. Concerningly, it has been shown that children prenatally exposed to alcohol who experience traumatic or distressing events show more severe neurodevelopmental deficits and a higher degree of co-occurring mental health issues compared to those who experience trauma but who do not have prenatal alcohol exposure (Henry, Sloane, & Black-Pond, 2007). Children prenatally exposed to alcohol also experience added difficulties with verbalizing such trauma due to various cognitive challenges that may be present (Gerteisen, 2008). It has been suggested that an increased stress response in individuals prenatally exposed to alcohol may explain the heightened impact of trauma compared to children with no alcohol exposure (Price, Cook, Norgate, & Mukherjee, 2017).

While participants diagnosed with FASD and those not diagnosed in the current study experienced trauma at a rate not statistically different from one another, neurodevelopmental impairment was greater in those who were diagnosed. Conversely, a greater number of children and youth not diagnosed with FASD had a diagnosis of PTSD compared to those diagnosed, which also suggests functional impairment. Taken together, these findings discussed support the heightened vulnerability of individuals with prenatal alcohol exposure, who experience trauma, and the important role of the environment to their later adjustment and mental health.

Neurodevelopmental Impairment

As expected, and in line with the Canadian Diagnostic Guidelines for FASD, individuals in the current study who received a diagnosis presented with greater neurodevelopmental impairment compared to those who did not receive a diagnosis. Noteworthy, while three areas of clinical impairment are needed to meet diagnostic criteria, 71.4% of the children and youth who received a diagnosis in this sample had four or more impaired domains, suggesting significant functional difficulty. Among areas of functioning, language, academic achievement, and cognition were the most common domains impaired, respectively. These domains are commonly reported as areas of difficulty among children and youth with FASD, and indicate areas of high demand for service (Rasmussen et al., 2008; Reid et al., 2017). The dispersed level of endorsement across all ten neurodevelopmental domains for individuals who received a diagnosis also further supports the known widespread impairment among this population, and thus, the multitude of services required (Paley & O'Connor, 2011).

For the children and youth who did not receive an FASD diagnosis in our sample, an average of one neurodevelopmental domain was clinically impaired. That being said, in 21.7% of cases two domains were significantly impaired, which falls just below the threshold for diagnosis. While not statistically significant, the neurodevelopmental domains most commonly impaired among this group did differ from those who received a diagnosis of FASD. More specifically, academic achievement, attention, and adaptive behaviour/social communication were most frequently impaired among this group. These findings indicate that while impairment at the clinical level was less widespread in those who did not receive an FASD diagnosis, for some participants functional challenges and service needs still existed.

Limitations and Considerations

While the current study allowed for a plethora of information to be identified for the first time about children and youth who have been prenatally exposed to alcohol in Northeastern Ontario, there are various limitations to be discussed. Most notably, the sample is strictly representative of children and youth under the age of 18 who have accessed the diagnostic service in Northeastern Ontario. Therefore, findings cannot be generalized to the broader FASD population in Northern Ontario, though research on this population as a whole is scarce. Essentially, it is possible that the profiles ascertained in the current study are reflective of children and youth that had more identifiable challenges and deficits, which could have precipitated the referral for FASD assessment. However, given the scope of the larger CanFASD National Database project, it is possible to explore overall trends among youth and adults with FASD using other participating Northern Ontario clinic data. Additionally, while use of the Database allowed for a comprehensive and reliable means for collecting and comparing data, information collected was thus limited to what could be extracted from the database.

More specifically, the majority of the variables chosen for this study provided specific responses to choose from, which did not allow for additional, and at times meaningful information to be ascertained. For example, when selecting areas of neurodevelopmental impairment no information regarding the degree of impairment was gathered. Therefore, domains that were approaching the range for clinical impairment could therefore not be determined. Likewise, for individuals who did not receive a diagnosis of FASD, it is unknown how their level of functioning compared to the threshold for a diagnosis. It is possible that for some participants, despite scoring above clinical cut offs required for a diagnosis, their level of functioning may still have been lower to that expected of them.

Lastly, an identified limitation in the current study was the inability to effectively capture areas of strength among participants because of the limited response choices. The inclusion of such information in research with the FASD population is important and has been argued to be a pivotal way in shifting the focus and subsequent views of individuals with FASD from a strictly deficit-based perspective (Flannigan, Harding, Reid, & Family Advisory Committee, 2018). In addition to this, the collection of information informing areas of strength and potential among individuals with FASD can also be particularly beneficial when incorporated into intervention methods to facilitate successful outcomes.

Conclusions

Results of the current study demonstrate a need to support children and youth prenatally exposed to alcohol in Northeastern Ontario, through a variety of informed services and support options. Findings further highlight the importance of not limiting such services to those with a confirmed diagnosis of FASD, and having services widely available, with a particular demand existing within the region's social service agencies. Most notably, behavioural and school-based interventions are needed, while social skills training and mental health supports are also justified. Education regarding prenatal alcohol exposure and the typical manifestations of FASD that is relevant and meaningful to professionals and service providers, such as medical practitioners and school educators, is also warranted. Fostering a greater awareness of FASD among professionals in the region may also help to lessen the age at which children and youth are currently being referred for assessment in Northeastern Ontario, and to facilitate early diagnosis and intervention. Lastly, findings indicate the need for mental health professionals in the region to appropriately screen individuals who have confirmed, or are suspected of having, prenatal alcohol exposure for mental health concerns, with appropriate attention being given to suicide

risk. Future research that delineates the specific difficulties and degree of impairment found in the current study could be particularly beneficial in tailoring existing, or informing new evidence-based interventions for this unique population in the region.

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Key messages from this article

People with disabilities: You deserve to have services and supports available to you that appropriately acknowledge your disability and address your needs.

Professionals: Professionals and service providers need to be educated on the implications of prenatal alcohol exposure and are encouraged to screen for this potential in their practices.

Policy Makers: There is a demand to service and support individuals with prenatal alcohol exposure and those with FASD through multiple service sectors within the Northeastern Ontario region.

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Tables

Table 1

Participant Demographic Characteristics by Diagnosis and Total Sample

Demographic Characteristic	FASD	No FASD	Total Sample
Gender			
Male <i>n</i> (%)	83 (65.9)	96 (57.8)	203 (62.3)
Female <i>n</i> (%)	43 (34.1)	70 (42.2)	123 (37.7)
Average age (<i>SD</i>)	*11.29 (3.61)	*10.16 (3.77)	10.24 (3.83)
Age variability <i>n</i> (%)			
0-5 years	6 (4.8)	16 (9.6)	32 (9.8)
6-12 years	72 (57.1)	101 (60.9)	196 (60.1)
13-17 years	48 (38.1)	49 (29.5)	98 (30.1)
Ethnicity			
Caucasian <i>n</i> (%)	41 (32.5)	65 (39.2)	122 (37.4)
Indigenous <i>n</i> (%)	85 (67.5)	101 (60.8)	204 (62.6)
Total <i>n</i> (%)	126 (38.7)	166 (50.9)	326 (100)

Note: Total Sample is reflective of all participants including those with an at risk designation who were not included in either comparative groups. *Significant difference in age between groups.

Table 2

The Profiles of Individuals Assessed for FASD at the Sudbury FASD Diagnostic Clinic

Database Item	Level of Endorsement n (%)		
	Overall Sample N = 326	FASD N = 126	No FASD N = 166
Referral Source			
Social Services	135 (41.4)	55 (43.7)	67 (40.4)
Medical Professional	111 (34.0)	36 (28.6)	57 (34.3)
Family	64 (19.6)	29 (23.0)	32 (19.3)
Education System	8 (2.5)	2 (1.6)	6 (3.6)
Legal System	6 (1.8)	3 (2.4)	3 (1.8)
Other	2 (.6)	1 (.8)	1 (.6)
Living Situation			
Foster Care	82 (25.2)	32 (25.4)	46 (27.7)
Adopted	78 (23.9)	32 (25.4)	38 (22.9)
Other Family Members	78 (23.9)	23 (18.3)	42 (25.3)
Biological Parents	74 (22.7)	32 (25.4)	33 (19.9)
Group Home	6 (1.8)	3 (2.4)	3 (1.8)
In Custody	4 (1.2)	3 (2.4)	1 (.6)
Other (Independent etc.)	4 (1.2)	1 (.8)	3 (1.8)
Reasons for Referral			
Behavioural Issues	276 (84.7)	106 (84.1)	139 (83.7)
Learning Difficulties	157 (48.2)	*81 (64.3)	*64 (38.6)
Social Skills Difficulties	156 (47.9)	*52 (41.3)	*90 (54.2)

Other (Eligibility for Supports, Follow up etc.)	81 (24.8)	40 (31.8)	34 (20.5)
Self Regulation Difficulty	78 (23.9)	33 (26.2)	36 (21.7)
Adaptive Living Problems	61 (18.7)	31 (24.6)	29 (17.5)
Developmental Delays	40 (12.3)	*22 (17.5)	*13 (7.8)
Difficulties with the Law	34 (10.4)	18 (14.3)	16 (9.6)
Mental Health Concerns			
Average Mental Health Concerns M (SD)	1.00 (1.52)	*2.00 (1.62)	*1.11 (1.37)
Range of Mental Health Concerns	0 – 7	0 – 7	0 – 6
Attention Deficit Hyperactivity Disorder	170 (52.1)	79 (62.7)	77 (46.4)
Oppositional Defiant Disorder	50 (15.3)	*17 (13.5)	*27 (16.3)
Suicide Ideation/Suicide Attempt	50 (15.3)	*29 (23.0)	*21 (12.7)
Intellectual Disability	48 (14.7)	*46 (36.5)	*2 (1.2)
Anxiety Disorder	26 (8.0)	13 (10.3)	9 (5.4)
Conduct Disorder	24 (7.4)	*19 (15.1)	*3 (1.8)
Attachment Disorder	21 (6.4)	10 (7.9)	9 (5.4)
Post Traumatic Stress Disorder	20 (6.1)	*6 (4.8)	*11 (6.6)
Mood Disorder	18 (5.5)	8 (6.3)	9 (5.4)
Autism Spectrum Disorder	12 (3.7)	9 (7.1)	3 (1.8)
Substance Abuse	9 (2.8)	3 (2.4)	5 (3.0)
Other Factors			
Trauma (e.g., reported abuse/neglect)	203 (62.3)	84 (66.7)	103 (62.0)

Note: For each case in the sample, more than one reason for referral and mental health concern could be selected. *Statistically significant difference between groups.

Table 3

Group Differences Across Neurodevelopmental Domains

Neurodevelopmental Domain	FASD % Impaired (n)	No FASD % Impaired (n)	p value	Cramers V
Motor Skills	46.3 (123)	7.3 (164)	< .001	.452
Neuroanatomy	19.7 (122)	2.4 (165)	< .001	.287
Language	76.6 (124)	11.9 (159)	< .001	.654
Academic	75.5 (110)	26.7 (120)	< .001	.487
Cognition	67.5 (123)	3.9 (155)	< .001	.677
Memory	48.2 (112)	1.9 (159)	< .001	.560
Executive Function	38.9 (95)	3.8 (105)	< .001	.435
Affect Regulation	10.7 (121)	8.4 (154)	.517	.039
Attention	50.5 (103)	14.1 (142)	< .001	.394
Adaptive Behaviour/Social Skills	69.4 (98)	11.3 (151)	< .001	.599

Examining the Intelligence Quotients and Related Adverse Outcomes among a Northeastern
Ontario Sample of Children and Youth with Fetal Alcohol Spectrum Disorder

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Abstract

Background

Past research examining the intellectual abilities of individuals with Fetal Alcohol Spectrum Disorder (FASD) has yielded unique findings with respect to Intelligence Quotients (IQ). Research has further highlighted issues in regards to IQ being a poor descriptor of an individual's overall functioning, particularly in the area of adaptive behaviour and related support needs. This study examined the IQ scores, adaptive behaviour, and adverse outcomes among a sample of children and youth with FASD in Northeastern Ontario, Canada.

Method

A total of 126 children and youth (ages 1- 17) with FASD were included. For each individual, a retrospective chart review was conducted and information was transferred into an online Database as part of a larger Canada wide study, and a secondary data analysis was employed. The National FASD Database is the only comprehensive method of collecting diagnostic information regarding FASD in the world, and collects a wide range of information related to reasons for referral, IQ, neurodevelopmental impairment, and adverse outcomes, which are explored in the current study. The relationship between age and adverse outcomes is also examined.

Results

Nearly half (43.7%) of the sample of children and youth with FASD had an IQ below 70, while 23.8% had an IQ of 71 and above. IQ was unable to be calculated in 32.5% of cases in the sample. IQ was not related to the rates of adaptive behaviour or majority of adverse outcomes in the sample ($p_s > .05$). Individuals in the sample with an IQ of 70 and below were found to have a higher frequency of difficulty with the law. Differences were also found with regard to age and adverse outcomes, with a greater proportion of participants aged 13-17 years of age presenting with mental health issues, previous suspension/expulsion from school, and difficulties with the law. Notably, among the overall sample, 65.1% of participants required a teacher's assistant in school, while 82.5% had a reported mental health concern.

Conclusions

Similar to past research, IQ was found to vary in our sample of children and youth with FASD and was unrelated to both rates of adaptive behaviour impairment and many of the adverse outcomes. These results support the weak ability of IQ in describing the populations' functional difficulties and needs. Results highlight the significant risk for children and youth within the region for adverse outcomes and the need for early identification and intervention methods, particularly in the areas of education and mental health. Adolescents with FASD experiencing difficulties with the law may also potentially benefit from available services in the criminal justice and legal systems.

Keywords: Fetal Alcohol Spectrum Disorder, Intellectual Disability, Intelligence Quotient, Developmental Disability, Adverse Outcomes, Services, Northeastern Ontario.

Examining the Intelligence Quotients and Related Adverse Outcomes among a Northeastern Ontario Sample of Children and Youth with Fetal Alcohol Spectrum Disorder

Background

Past research has demonstrated that the intellectual abilities of individuals with Fetal Alcohol Spectrum Disorder (FASD) vary (Kingdon *et al.* 2016; Mattson *et al.* 2011; Rasmussen *et al.* 2006; Streissguth *et al.* 2004). Likewise, among children with FASD, intelligence scores (i.e., IQ) have been found to range from 64 to 99, with an average score of 84 (Kingdon *et al.* 2016). Among an adult sample, IQ scores fell between 59 and 108, with an average score of 79.9 (Temple *et al.* 2011). Thus, for individuals with FASD, intellectual functioning can be classified as being in the intellectual disabled to average range of intelligence (Sattler 2018).

A consistent finding throughout the literature is that individuals with FASD are often not defined as having an Intellectual Disability (ID), typically reported to be a result of having IQ's above 70 (Davis *et al.* 2017; Mattson *et al.* 2011; Streissguth *et al.* 2004). Using information gathered through a systematic literature review investigating comorbid disorders in FASD, researchers estimate that intellectual disability occurs in 23% of the FASD population (Weyrauch *et al.* 2017). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a diagnosis of an ID requires both deficits in intellectual functioning, derived from a clinical assessment and standardized intelligence testing (yielding an IQ of 70 or below with a standard error measurement of 5) and deficits in adaptive behaviour, which include daily living skills, socialization, and communication abilities (American Psychiatric Association [APA] 2013). While individuals with FASD may exhibit intelligence scores above what is considered to be an ID, many still significantly struggle in areas important for everyday function, and often

score poorly on measures of adaptive behaviour (Brown *et al.* 2018; Clarke and Gibbard 2003; Crocker *et al.* 2009; Streissguth *et al.* 2004). For example, despite having an IQ in the low average range (i.e., 80), individuals with FASD have demonstrated adaptive skills equivalent to individuals with IQ scores between 60 to 70, or within the ID range (Brown *et al.* 2018; Crocker *et al.* 2009; Edwards and Greenspan 2010). In further support of this discrepancy, researchers have reported no significant correlation between the IQ scores of individuals prenatally exposed to alcohol and adaptive behaviour measures (Carr *et al.* 2010; Thomas *et al.* 1998; Whaley *et al.* 2001). For individuals with FASD, deficits in adaptive behaviour, coupled with additional neurodevelopmental impairments specific to prenatal alcohol exposure, such as lower IQ, together warrant the need for services and supports that are comprehensive and lifelong (Greenspan *et al.* 2016; Paley and O' Connor 2009)

Having a diagnosis of an ID, otherwise known as a Developmental Disability (DD) in Ontario, can grant an individual access to a range of government funded services, including financial assistance, respite care, housing support, as well as community and employment opportunities (Developmental Services Ontario 2019; Government of Canada 2019). Such services are often sought after by families of individuals with FASD as specific FASD services are not always offered, nor do they provide the depth or breadth of support required throughout the lifespan (Greenspan *et al.* 2016; Petrenko *et al.* 2014). What becomes problematic for individuals with FASD and their families is that many are not eligible for developmental services based on their higher IQ, despite their paralleled need to those with an ID (Greenspan *et al.* 2016; Petrenko *et al.* 2014; Streissguth *et al.* 2004). Access becomes even more crucial when these individuals transition into adulthood, a time when less support is typically provided and the demands for independent living increase (Coons 2013). Concerningly, deficits in adaptive skills

functioning among this population have been shown to worsen with age, with specific research demonstrating the adaptive skills of an adolescent with FASD to be equal to those of a typical seven year old (Rasmussen *et al.* 2008; Streissguth *et al.* 1991). Likewise, adults with FASD are reported to frequently struggle with daily living skills, including medical care, managing money, obtaining and maintaining employment, and safe housing (Coons 2013).

Given that individuals with FASD may experience deficits in adaptive behaviour, regardless of intelligence, IQ scores are considered to be a poor measurement of functioning among this population and do not accurately describe service needs for this population (Greenspan *et al.* 2016). Furthermore, contrary to how IQ is typically viewed, a score above 70 is seen as a risk factor for individuals with FASD as it lessens contact to appropriate services, which has been associated with various adverse life outcomes (Rasmussen *et al.* 2008; Streissguth *et al.* 2004). Such outcomes that occur frequently within this population include mental health issues, difficulties in school, trouble with the law, alcohol and drug use issues, and inappropriate sexual behaviours (Brown *et al.* 2018; Streissguth *et al.* 2004). Concerningly, the persistence and severity of such outcomes have been found to increase after initial onset and without targeted supports, with an even greater risk noted among adolescents (Pei *et al.* 2011; Streissguth *et al.* 2004).

Therefore, the purpose of the current study was to examine the IQ scores and related outcomes among a sample of children and youth diagnosed with FASD in Northeastern Ontario, Canada. More specifically, a region where there is limited research on the prevalence, common characteristics, and the subsequent services that are utilized and that effectively meet the needs of those with FASD (Coons *et al.* 2017). Specific aims included to determine the range of IQ scores among participants and the proportion of individuals who had a diagnosis of ID in this

region. Differences in the rates of adaptive behaviour deficits and adverse outcomes were also examined between participants' IQ and age. The current study further explored the IQ's of individuals with FASD who did not have a diagnosis of ID and the proportion of adaptive behaviour impairment among this subgroup to assess for potential difficulties in obtaining developmental services.

Methods

Participants

A total of 126 children and youth (ages 1 –17) who were assessed for and received, an FASD related diagnosis in Northeastern Ontario were included in the current study. The sample consisted of greater number of males (65.9%) than females (34.1%), with individuals on average being 11.29 (SD = 3.61) years of age. A full summary of the sample's demographic information is displayed in Table 1.

Procedure

As part of a Canada wide study conducted by the Canada FASD Research Network investigating the profile of Canadians who present for an FASD assessment, a retrospective chart review and secondary data analysis of children and youth who were assessed for FASD at the Sudbury FASD Diagnostic Clinic in Northeastern Ontario was conducted. The Sudbury diagnostic clinic is the only diagnostic service in the region and assesses children and youth under the age of 18. For each participant, referral and diagnostic assessment information was reviewed and inputted into an online, comprehensive Database through the secure web base, Redcap. After all accessible charts were reviewed and Database records were submitted, a request for data for specific Database items (i.e., participant demographics, intelligence quotients, adverse outcomes, and neurodevelopmental domain impairment, as per the Canadian

FASD Diagnostic guidelines) was sent by the principal investigator of this study to the principal investigators of the larger study to permit access to the Northeastern Ontario data.

Ethics

Ethical approval for the current study was obtained through the Laurentian University Ethics Board, Ontario, Canada, which follows Tri-Council recommendations for Research with Human Participants [REB #60149B4].

Data Analysis

Data were analysed using Statistical Package for the Social Sciences (SPSS) edition 24. Descriptive analyses and chi-square tests were performed to gain insight into this sample of children and youth with FASD, with respect to their intellectual functioning, adaptive behaviour, and adverse outcomes.

Results

Intelligence Quotient Scores

A frequency count was run to determine the Full Scale Intelligence Quotient (FSIQ) scores of individuals in the sample. Results revealed that the majority of children and youth with FASD presented with a FSIQ of 70 and below (43.7%) followed by a FSIQ between 71- 85 (15.9%), while an additional 7.9% of individuals had a FSIQ above 85. In 32.5% of cases in the current sample FSIQ could not be calculated, and information regarding the reasons for this was not available in the Database. For remaining analyses the variables IQ of 71-85 and IQ above 85 were combined to form the group “71 and above” to allow for balanced group comparisons.

Intellectual Functioning and Adaptive Behaviour

A frequency count was run to determine the number of individuals diagnosed with FASD (n = 126) who had an ID diagnosis. Results indicated that 46 (36.5%) children and youth in the

sample had an ID diagnosis. Separate frequency counts were then performed using individuals with FASD who did not have an ID diagnosis to determine their IQ and the proportion of whom had deficits in adaptive behaviour, as indicated by significant impairment in the adaptive domain included in the Canadian FASD Diagnostic Guidelines (determined using the Adaptive Behavior Assessment System-Third Edition and clinical judgment; Cook *et al.* 2016). Results revealed that for individuals with FASD and no ID diagnosis ($n = 69$), 13 (18.8%) had an IQ of 70 and below, 26 (37.7%) had an IQ of 71 and above, and IQ was unknown in 30 cases (43.5%). Of those individuals with FASD and no ID diagnosis ($n = 69$), 36 (52.2%) had significant impairment in the adaptive behaviour domain.

A chi-square analysis was performed to determine if individuals with an IQ of 70 and below, those with an IQ of 71 and above and those with an IQ that could not be calculated differed on the frequency of adaptive domain impairment. Results indicated no significant difference on adaptive behaviour impairment between these groups, [$\chi^2 (1, n = 98) = .207, p = .902$]. [IQ of 70 and below: 67.4%, IQ of 71 and above: 72.7%, IQ uncalculated: 70.0%].

Co-occurring Adverse Outcomes

Frequency counts were run to determine the proportion of individuals in the overall sample ($N = 126$) who were experiencing various adverse outcomes. Results revealed that over half of the sample of children and youth with FASD (65.1%) required a teacher's assistant in school, 30.8% had previously been suspended/expelled from school, while 82.5% of the sample had a reported mental health concern. Separate chi-square analyses were subsequently run to examine potential differences in the rates of the adverse outcomes when individuals were grouped according to their IQ (70 and below, 71 and above, and IQ uncalculated). Results revealed no significant differences between the IQ groups for the following adverse outcomes;

mental health concerns, required teacher's assistant, and suspension/expulsion (all $p_s > .05$).

However, a significant finding was found for difficulty with the law (defined as being an offender), [$\chi^2(4, n = 126) = 10.33, p = .035$]. Significantly more individuals with FASD and an IQ of 70 and below (25.5%) experienced difficulties with the law compared to those with an IQ of 71 and above (16.7%), and individuals with IQ not calculated (17.1%). Results for adverse outcomes in the overall sample and by IQ are presented in Table 2.

Differences in the rates of adverse outcomes between males and females were subsequently explored using chi-square tests and no significant differences were found (all $p_s > .05$). In the current sample, males with FASD and females with FASD experienced similar rates of requiring a teacher's assistant (Male: 67.5%, Female, 61.9%), school suspensions/expulsions (Male: 34.9%, Female, 20.9%), difficulty with the law (Male: 15.7%, Female: 11.6%), and mental health concerns (Male: 85.5%, Female: 80.5%).

Additional chi-square analyses were run to determine differences in the rates of adverse outcomes when children and youth with FASD ($n = 126$) were grouped by their age (0-5, 6-12, and 13-17). Results indicated that significantly more individuals aged 13-17 years (89.4%) had reported mental health concerns compared to individuals 0-5 years (40.0%) and individuals 6-12 years (83.3%) [$\chi^2(2, n = 124) = 8.18, p = .017$]. A significantly greater proportion of individuals aged 13-17 years (72.7%) had also been suspended/expelled from school compared to those 6-12 years (40.4%) and 0-5 years (20%) [$\chi^2(2, n = 79) = 8.17, p = 0.17$]. Likewise, significantly more individuals aged 13-17 years (43.8%) had difficulties with the law compared to individuals 6-12 years (6.9%) and 0-5 years (0%) [$\chi^2(2, n = 126) = 31.875, p < .001$]. Groups did not significantly differ on requiring a teacher's assistant in school (0-5 years, 50.0%, 6-12 years, 81.2%, 13-17 years, 69.7%).

Discussion

The FSIQ ranges for individuals in the current study support the varying levels of intelligence previously noted among individuals with FASD in the literature (Kingdon *et al.* 2016; Mattson *et al.* 2011; Reid *et al.* 2017). Notably, almost half of the children and youth in the current sample had a FSIQ within what is considered to be the intellectually deficient range (70 and below), while the remaining participants' FSIQ scores could be classified as being in the borderline to average ranges, suggesting weaker to sufficient cognitive abilities (Sattler 2018). The proportion of children and youth in the sample with IQ scores of 70 and below lends additional support to the degree of functional difficulties and specific service needs identified among the same sample of participants in Northeastern Ontario reported in Burns *et al.* (in preparation).

An important finding was that in 32.5% of cases, participants' FSIQ scores could not be calculated. While the reasoning for why IQ could not be determined in the current study is largely unknown, findings from previous research provide a plausible explanation. Researchers have identified a significant difference between the verbal and non-verbal or performance intelligences of children with FASD (Mattson *et al.* 2011; Rasmussen *et al.* 2006). Additionally, other researchers have found that children prenatally exposed to alcohol perform more poorly on cognitive assessment tasks that are "intellectually demanding", such as those that require practical reasoning (Adnams *et al.* 2001). In such cases of discrepant scores on tasks or areas of ability on an IQ test, like the commonly used Wechsler Intelligence Scales that were employed in the current study, not reporting the FSIQ is considered best practice (Sattler 2018). In other words, it is possible that participants demonstrated varying strengths and weaknesses within their

overall cognitive profile, and as a result the FSIQ was not an accurate indicator of their general intellectual abilities.

However, it is also important to consider the very nature of assessing children and youth with FASD and the potential role of factors associated with the disorder that may help to explain this finding. As reported by Coons (2013), children with FASD, regardless of IQ scores, may have difficulty meeting expectations or completing tasks that include multiple steps, as a result of deficits in executive function and working memory. Other difficulties typically seen within the FASD population, such as inattention, impulsivity, and poor self-regulation (Kodituwakku 2009; Rasmussen *et al.* 2008) can also all be argued to significantly limit one's ability to attend to, comply with, and complete tasks that are required as part of intelligence testing. Altogether, the finding that FSIQ could not be calculated in almost one third of cases within the current study provides evidence towards potential difficulties in actually obtaining a measure of overall intellectual functioning that may be unique to children and youth with FASD. Consequently, barriers in assessing cognitive functioning, as well as difficulties yielding a representative IQ score, can be argued to pose potential challenges for professionals in terms of accurately diagnosing ID among this population, and in turn may impede individuals' eligibility for services.

Within Northeastern Ontario, where the current study was conducted, families with a child who have an ID can receive financial assistance, psychological services, respite, and specialized classroom placements in school (Child and Community Resources 2019; Compass 2019). Adolescents with an ID can access specific transitional supports into adulthood, a time previously identified as especially difficult for individuals with FASD (Coons 2013), and into adulthood they can receive a variety of financial, community, and housing support services

(Sudbury Developmental Services 2014). Not surprisingly, accessing developmental services has been previously identified as a need for families of individuals with FASD in Northeastern Ontario, and an additional stressor when the individual does not qualify because of their IQ (Watson *et al.* 2013). Considering this information in light of the current study, only 36.5% of children and youth with FASD in the sample would qualify for developmental services having been diagnosed with an ID. Conversely, for those without this comorbid diagnosis, obtaining developmental services may be well justified but difficult to obtain. Challenges accessing services for individuals with FASD and their families extend beyond Northeastern Ontario with issues such as lack of FASD resources, required formal diagnosis, and extensive waitlists reported in other regions of Canada (Goodman *et al.* 2014; Pepper *et al.* 2018).

Results in the current study indicated that for individuals with FASD who did not have a separate ID diagnosis, only 18.0% had an IQ below 70, while 52.2% had significant impairment in adaptive behaviour, suggesting high levels of care needs, in areas such as self-care, communication, and socialization. These findings lend further support, from a diagnostic perspective, to the previously identified issue regarding access to appropriate services for individuals with FASD and their families (Pepper *et al.* 2018; Watson *et al.* 2013). Furthermore, considering the age of individuals in the current study in light of past research on adaptive skills and developmental trajectory (e.g. Streissguth *et al.* 1991), it can be expected that these deficits will worsen over time, and needs may therefore increase. Thus, the results highlight the problematic nature of IQ being the main gateway to comprehensive services for individuals with FASD in the region, particularly those that can support these individuals in their everyday living.

The finding that the rate of adaptive behaviour deficits did not differ based on participant's IQ scores including those uncalculated parallels past research, which has found the

two to be poorly associated (Carr *et al.* 2010). Similarly, IQ was also not significantly related to the adverse outcomes of mental health concerns, requiring a teacher's assistant, and school suspension/expulsion. Having an IQ below 70 in the current sample was however associated with increased rates of difficulty with the law. This finding may be supported by the increased difficulties with executive function, cause and effect reasoning, and decision-making individuals with FASD may already experience and may be exacerbated by impaired cognitive functioning (Rasmussen *et al.* 2008). Though contrary to the literature that suggests individuals with FASD with an IQ above 70 are at greater risk of experiencing adverse outcomes (Streissguth *et al.* 2004), individuals in the current study were undergoing FASD assessment at the time this information was collected. Thus, the children and youth in the current study had potentially not yet been connected to appropriate services, which typically accounts for the fewer difficulties among those with FASD and an IQ below 70 (Streissguth *et al.* 2004). Interestingly, IQ was neither a risk nor protective factor against many of the adverse outcomes among this sample of children and youth with FASD, suggesting its weak ability to reflect or predict support needs.

Beyond IQ, one of the strongest correlates to adverse life outcomes documented within the FASD literature is a diagnosis past the age of 6 years old (Rasmussen *et al.* 2008; Streissguth *et al.* 2004). Additionally, receiving a diagnosis later than the age of 12 has been associated with an even greater likelihood of experiencing adverse outcomes (Streissguth *et al.* 2004). These findings were exemplified in the current study with individuals 13-17 years of age presenting with significantly greater rates of mental health concerns, school suspension/expulsion, and difficulties with the law compared to younger individuals at the time they present for a diagnosis. Factors associated with age, such as increased independence, selection of peer groups, as well as tolerance of behaviour in schools for older youth may also account for these findings.

Results lend additional support to the importance of an early diagnosis as fewer adverse outcomes (i.e., mental health concerns, school expulsions, requiring a teacher's assistant) were found to exist among individuals 0-5, with a marked increase in these rates among individuals 6-12 years. Altogether, children and youth with FASD within Northeastern Ontario are receiving a diagnosis, on average, well past what is considered to be the optimal age for fewer adverse outcomes, and as a result have increased mental health or behavioural difficulties by the time they are connected to the diagnostic service. Given what is known about the persistence and severity of these outcomes after initial onset, the results of this study highlight the need for early screening and intervention efforts targeted towards children and youth with confirmed or expected prenatal alcohol exposure in the region.

Considering the various adverse outcomes in the current study, an area of significant difficulty among participants seems to be related to school. More specifically, regardless of individuals' age, a large proportion required a teacher's assistant. Neurodevelopmental impairments, as well as behavioural and mental health needs previously identified within this sample of children and youth (Burns *et al.* in preparation), may serve to support this finding. Collectively, the substantial and equivocal rate at which participants required assistance in school, as well as the rate of school expulsions within the sample, speaks to a potential need within the education system for supports or accommodations that are appropriately informed and tailored for students with FASD. More specifically, individualized academic interventions that acknowledge cognitive deficits and developmental needs while promoting everyday skill development are found to be effective, along with informed behavioural plans (Millians 2015). Results also demonstrate a demand for services in the areas of mental health for children and youth with FASD, as well as services within the criminal justice or legal systems to support

adolescents, experiencing difficulties with the law, with specific attention and support warranted for those with FASD with intellectual deficits.

Limitations and Considerations

The current study has several limitations to be discussed. First, the categorical nature of IQ limited our understanding of individuals' actual IQ scores and, as a result, the precise range of intellectual abilities within this sample is unclear. Likewise, the categorization of IQ above 85 was very broad in nature and did not allow us to meaningfully capture the proportion of individuals with IQ's within or above the average ranges. Additionally, the collection of strictly FSIQ limited our insight into participants' full cognitive profiles, as well as potential patterns of cognitive strengths or weaknesses among the sample, which could be exceedingly useful in informing intervention and management strategies. A separate limitation is the lack of reasoning for why FSIQ could not be calculated. Obtaining this information could potentially speak to difficulties related to assessing children and youth with FASD or issues with the psychological measures being utilised. It is possible that results may support a previous argument within the literature regarding the use of additional or differential standardized measures when assessing the cognitive functioning of individuals with FASD (Brown *et al.* 2018). Despite these limitations, our findings provide meaningful information regarding children and youth with FASD in a specified region that previously has received minimal attention.

Conclusion

To our knowledge, this exploratory study is the first to examine the intelligence scores and related outcomes among a sample of individuals with FASD in Northeastern Ontario. Similar to existing research in this area, results identified variability in intellectual functioning, as well as difficulties with IQ being an accurate indicator of functioning and related needs.

Furthermore, results revealed an area of potential concern related to ascertaining the FSIQ among children and youth with FASD, which may warrant further investigation in future research. Findings also showed that children and youth with FASD within the region are at substantial risk for experiencing adverse outcomes, which may be a direct result of delayed access to the diagnostic service and increased age. The need for increased services in multiple sectors, particularly education, mental health, and criminal justice or legal systems, for children and youth with FASD within Northeastern Ontario are further supported by our findings.

Conflict of Interest

The authors report no conflicts of interests and are together responsible for the contents of this paper.

Tables

Table 1. Participant Demographic Characteristics

Demographic Characteristics	
Gender	
Male <i>n</i> (%)	83 (65.9)
Female <i>n</i> (%)	43 (34.1)
Average age (SD)	
Age range	11.29 (3.61) 1 – 17
Ethnicity	
Indigenous <i>n</i> (%)	85 (67.5)
Caucasian <i>n</i> (%)	41 (32.5)
Neurodevelopmental	
Impairment <i>M</i> (<i>SD</i>)	4.53 (1.53)
Range of impairment	1 – 9
Referral Source <i>n</i> (%)	
Social services agencies	55 (43.7)
Medical professional	36 (28.6)
Family	29 (23.0)
Legal system	3 (2.4)
Education	2 (1.6)
Other	1 (.8)

Table 2. Rates of Adverse Outcomes in the Overall Sample and by Participants IQ

Adverse Outcome	Overall Sample n = 126	FSIQ score		
		70 and below n = 55	71 and above n = 30	Not calculated n = 41
*Mental Health <i>n</i> (%)	104 (82.5)	50 (92.5)	24 (80.0)	30 (75.0)
Teacher's Assistant <i>n</i> (%)	82 (65.1)	37 (67.3)	18 (60.0)	27 (65.9)
Suspension/Expulsion <i>n</i> (%)	38 (30.2)	13 (23.6)	11 (36.7)	14 (34.1)
Difficulty with the Law (i.e., offender) <i>n</i> (%)	26 (20.6)	*14 (25.5)	*5 (16.7)	*7 (17.1)

Note: Information for mental health was missing in two cases (70 and below, *n* = 54; Not calculated *n* = 40) *Reported mental health concern included on the National Database (i.e., ADHD, ID, Attachment disorder, Anxiety disorder; Autism Spectrum Disorder, Bipolar disorder, Obsessive Compulsive Disorder, Mood disorder, Conduct disorder, Oppositional Defiant Disorder, PTSD, Substance abuse disorder, Suicide attempt/suicidal ideation) *Statistically significant difference between IQ groups for difficulty with the law.

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Chapter 4: Conclusion

The aim of this paper-based thesis was to provide information, for the first time, on the diagnostic outcomes and support needs of individuals with prenatal alcohol exposure who present for an FASD assessment in Northeastern Ontario. In this chapter, the findings from the two papers are summarized and then presented in line with the research questions outlined in chapter one. This chapter concludes with suggestions for future research as well as clinical and practical implications.

Summary of Paper 1

The first article titled “Fetal Alcohol Spectrum Disorder in Northeastern Ontario: A Descriptive Examination of Who is Assessed, Who Receives a Diagnosis, and Who Does Not”, employed a retrospective chart review and secondary data analysis to examine the diagnostic profile of children and youth in Northeastern Ontario who presented for an FASD assessment. In this paper, I investigated the differences in diagnostic outcomes between individuals diagnosed with FASD and those not diagnosed. Despite a spectrum of deficits associated with FASD (e.g., Cook et al., 2016), little is currently known about the functional difficulties and areas of support need among this population in Northeastern Ontario. Researchers have argued that the comprehensive and universal collection of diagnostic information specific to individuals assessed for FASD across various diagnostic locations could be an effective way to describe patterns of deficits and address service demands within this population (Clarren et al., 2015). As part of a larger Canada wide study aiming to identify a profile of individuals with FASD, secondary data representative of 326 children and youth assessed for FASD in Northeastern Ontario were collected and used in this study. The findings reveal a range of deficits and multi-service and

support needs among children and youth prenatally exposed to alcohol in the region, with greater severity and demand evident in those who received a diagnosis of FASD compared to those who did not.

Understanding the demographic characteristics of individuals accessing the FASD diagnostic service in the Northeastern Ontario region is important in ensuring services are available, appropriate, and accessible to those who are in need of them. In our study, Caucasian and Indigenous individuals were diagnosed with FASD at a similar rate; however, a search conducted through Ontario's FASD service directory points to a lack of supports for non-Indigenous families in the region (FASD Ontario, 2019). While Caucasian families do have access to a range of services that are primarily designed and targeted to Indigenous families, it could be argued that these may not meet their needs entirely as they are often community specific and culturally driven. Of the listed services that are not Indigenous specific, information and assistance with accessing services is primarily offered, with no mention of direct one-to-one support (FASD Ontario, 2019). Additionally, many of the services listed as available within the region require confirmed or suspected FASD for eligibility which, when considering that half of the individuals in the current study with prenatal alcohol exposure presented with difficulties but did not receive a diagnosis, indicates an additional barrier for families in Northeastern Ontario. A significantly greater number of available supports targeted directly to Indigenous populations can also be viewed as problematic, as it reinforces the stereotype that FASD occurs exclusively or at disproportionately higher rates among Indigenous peoples (Flannigan, Unsworth, & Harding, 2018).

It is also important to acknowledge the differences in terms of support need among those coming from different living situations. Findings from the current study reveal that many

children and youth who accessed the FASD diagnostic service were in foster care or had been adopted. Foster and adoptive families caring for individuals with FASD have been found to report greater levels of stress, fatigue, and burnout compared to biological families (Paley, O'Connor, Frankel, & Marquardt, 2006; Reid & Moritz, 2019; Rowbottom, Merali, & Pei, 2010). Non-biological caregivers also deal with frustration and anger when acknowledging that their child's difficulties could have potentially been prevented, which is reported to increase feelings of burnout (Olson, Oti, Gelo, & Beck, 2009). Not surprisingly, access to respite services, help with accessing and obtaining school supports, being kept current on up-to-date FASD information, and forming supports with other families raising children with FASD have all been identified by foster and adoptive families as important factors in keeping placements stable (Brown, Sigvaldason, & Bednar, 2005; Pepper, Coons-Harding, Bibr, & Watson, 2018).

The need for safe and appropriate respite services has been similarly reported by biological families in Northern Ontario (Watson, Hayes, Coons, et al., 2013), and in the current study almost a quarter of children and youth were living with their biological parents. Although a province-wide respite service is available within the region for families caring for an individual with a disability, the online service description cautions that persons with FASD may or may not qualify (FASD Ontario, 2019). Past researchers have also reported that biological families deal with additional challenges such as stigmatization and feelings of guilt or shame (Paley et al., 2006; Popova, Lange, Burd, & Rehm, 2015; Watson, Hayes, Coons et al., 2013). Thus, additional or differential family support and services may be warranted depending on the relationship the caregiver has with the child prenatally exposed to alcohol. In the current study, the degree of neurodevelopmental impairment noted among participants lends additional support

to the need for targeted supports for the individual with FASD, as well as for supports such as respite for the family unit.

Although this study addressed the importance of discerning a diagnostic profile of individuals prenatally exposed to alcohol and those diagnosed with FASD in an effort to inform service and intervention efforts, findings are strictly reflective of children and youth assessed for FASD in the region. The author of this thesis therefore cautions the transferability of findings to the broader FASD population in Northern Ontario and suggests that research examining the population of adults prenatally exposed to alcohol in the region is warranted. The diagnostic clinic in Sudbury only assesses children and youth, and therefore adults in the region seeking a diagnosis must travel to Thunder Bay or Toronto for this service. Research examining the differences between the youth and adult population with respect to the deficits and challenges experienced, who receives a diagnosis of FASD, the nature of services and supports required, and where services are most needed could collectively help to ensure that appropriate, well-balanced support is available and accessible within the region to all individuals prenatally exposed to alcohol experiencing difficulties.

Summary of Paper 2

The second article titled, “Examining the Intelligence Quotients and Related Adverse Outcomes Among a Northeastern Ontario Sample of Children and Youth with Fetal Alcohol Spectrum Disorder”, was a continuation of the first article previously described. While the first article focused on the overall sample of individuals prenatally exposed to alcohol who presented for an FASD assessment in Northeastern Ontario, this study focused exclusively on the 126 children and youth who received a diagnosis of FASD. Employing the same methodology as the

first article, this article demonstrated that the IQ scores of individuals with FASD varied and that IQ was unrelated to adaptive behaviour impairment and several adverse outcomes including, mental health concerns, requiring a teacher's assistant, and school expulsion. In our sample, an IQ of 70 and below was associated with increased rates of difficulty with the law. Similar to previous findings demonstrated within the FASD literature (e.g., Streissguth et al., 2004), age was significantly related to adverse outcomes in our study.

This article was an effort to address whether the unique and challenging aspects commonly reported with IQ and with age were evident in a Northeastern Ontario sample of individuals with FASD. Despite a great deal of evidence within the FASD literature supporting the problematic nature of IQ, particularly concerning service eligibility, few efforts have been made to address and rectify this ongoing issue (Greenspan et al., 2016). Despite not having insight into participants' overall cognitive profiles (i.e., scores beyond FSIQ), our findings still provide additional evidence that among children and youth with FASD, IQ weakly accounts for functional difficulties and adverse outcomes. Furthermore, findings indicate that within Northeastern Ontario individuals with FASD and their families are likely to face barriers when attempting to access developmental services. Our findings also underscore the importance of an early diagnosis of FASD, specified as before the age of six (Streissguth et al., 2004), to lessen later adverse outcomes (e.g., mental health concerns, difficulties with the law, school suspension/expulsion).

Discussion in Relation to the Research Questions

In summary, the findings discussed here have addressed the research questions outlined in chapter one by contributing the following results: 1) Children and youth prenatally exposed to

alcohol presented for an FASD assessment in Northeastern Ontario at the average age of 10 years old and were either of Indigenous (62.6%) or Caucasian (37.4%) descent. A greater number of males (62.3%) were seen compared to females (37.7%). Individuals were referred mainly from social service agencies or medical practitioners. The majority of children and youth lived in foster or adoptive care, though family members were also reported as common caregivers. Children and youth with prenatal alcohol exposure were referred for an FASD assessment most consistently because of behavioural concerns, learning difficulties, and social skills difficulties. Mental health concerns were also evident with some variability among the overall sample, with ADHD, ODD, and past suicidal attempt or ideation being reported most frequently. A significant proportion of those assessed for FASD had identified trauma, and individuals presented, on average, with two neurodevelopmental domains significantly impaired.

In addressing the second research question, the following information was obtained: 2) Children and youth who received a diagnosis of FASD and those who did not were not significantly different in terms of gender or ethnicity; however, the children and youth who received a diagnosis of FASD were older than those who did not receive a diagnosis. The children and youth who received a diagnosis and those who did not lived in similar living situations, and were referred for an FASD assessment by similar sources. Individuals with FASD were referred more commonly because of learning difficulties and developmental delays, while children and youth not diagnosed were referred more often because of social skills difficulties. Those diagnosed with FASD presented, on average, with two mental health concerns while those not diagnosed had, on average, one mental health concern. The children and youth with FASD were more likely to have a diagnosis of Conduct Disorder and had experienced a previous suicidal attempt or suicidal ideation. Conversely, those not diagnosed with FASD were more

likely to have a diagnosis of ODD or PTSD. The children and youth diagnosed with FASD and those not diagnosed experienced similar rates of trauma. As expected, neurodevelopmental impairment was greater in those diagnosed with FASD compared to those not diagnosed with language, academic achievement, and cognition being the most common domains of impairment, respectively.

The third and final research question was addressed with the following information: 3) The IQ scores among our Northeastern Ontario sample of children and youth with FASD were within the ranges of 70 and below (43.7%), 71-85 (15.9%), and above 85 (7.9%). However, in 32.5% of cases, IQ could not be calculated. The sample was then grouped and referred to in respective analyses by their IQ being 70 and below, 71 and above, and not calculated. Among our sample of children and youth with FASD, 36.5% had a diagnosis of intellectual disability. Rates of adaptive behaviour impairment did not differ according to participants' IQ scores and rates for adverse outcomes, including mental health concerns, requiring a teacher's assistant in school, and school expulsion. An IQ of 70 and below in our sample was associated with increased rates of difficulties with the law. Furthermore, rates of mental health concerns, school expulsion, and difficulties with the law were higher among individuals 13 to 17 years of age compared to individuals 0 to 5 and 6 to 12 years of age. Regardless of IQ, individuals with FASD experienced similar rates of requiring a teacher's assistant in school. Together, the findings presented in this thesis provide insight into this subset of the FASD population in Northeastern Ontario and can direct future researchers to areas of specific interest.

Suggestions for Future Research

In an effort to expand upon the findings described in the current study, future researchers should seek to examine individuals given an at risk designation. To clarify, individuals receiving this designation do not meet the threshold for FASD diagnosis, however prenatal alcohol exposure is confirmed, and evidence of neurodevelopmental impairment is present (Cook et al., 2016). Though the current study initially aimed to compare this group of individuals, information collected from the Dataform that was specific to this group was limited because of the amount of missing data. Given its addition in the revised diagnostic guidelines (Cook et al., 2016), it would be advantageous for researchers to examine the patterns of presenting concerns, primary deficits, and service needs of those who receive this designation. Comparing these outcomes to individuals who receive an FASD diagnosis and those who do not can also identify differing strengths (e.g., memory), weaknesses (e.g., language), and required supports (e.g., educational assistant). It is very likely that, as outlined in the diagnostic guidelines, many children in Northeastern Ontario who receive this designation are very young at the time they are assessed for FASD (Cook et al., 2016), which has been found to complicate the FASD assessment process (McLachlan, Andrew, Pei, & Rasmussen, 2015). However, addressing the developmental and functional needs of this particular group of individuals is seemingly crucial, given that early detection and intervention is key in maximizing later outcomes in those with FASD (Streissguth et al., 2004) and that FASD informed services are recommended with this designation (Cook et al., 2016).

Future researchers should also seek to investigate the long-term experiences and outcomes of individuals who receive a diagnosis of FASD, those given an at risk designation, as well as those who do not receive an FASD related diagnosis. These findings could be useful in

further understanding the trajectory of possible outcomes, assessing what difficulties tend to increase, decrease, or remain stable over time, and whether these outcomes change with or without supports. Results may also identify sensitive developmental periods, such as the transition into adulthood, previously reported to be difficult for individuals with FASD (Coons, 2013), that could warrant additional or increased supports. Following individuals given an at risk designation long term would also provide unique insight into whether the individual later receives an FASD diagnosis, and what the emerging deficits entail. Lastly, obtaining this information can be useful in addressing the clinical utility of the designation and whether it is helpful in addressing and remediating identified issues.

An interesting finding in our study, and an area worth exploring in future research, was that a greater number of males compared to females presented for and received an FASD diagnosis in the region. In the case of other neurodevelopmental disorders, such as Autism Spectrum Disorder, Intellectual Disability, and ADHD, it has been well established that males are more likely to receive these diagnoses (American Psychiatric Association [APA], 2013). Within the FASD literature, differences in the prevalence rate of FASD between males and females is largely unclear, with some researchers reporting no gender differences (Herman, Acosta, & Chang, 2008), while other researchers have reported higher rates among males, specifically in Canada (Thanh, Jonsson, Salmon, & Sebastianski, 2014). It is possible that the propensity for males to exhibit greater externalizing symptoms compared to females (APA, 2013; Ara, 2016) may explain why they are referred, assessed, and potentially receive a diagnosis of FASD more frequently. Though in our sample externalizing disorders such as CD and ODD did not differ statistically between males and females, a higher number of males were noted in these samples, which may lend some support to this possibility. Future research

investigating the potential difference in the prevalence, as well as the presentation, of FASD between males and females can be useful in ensuring individuals are correctly identified, and that appropriate services are provided.

Clinical and Practical Implications

The estimated 4% prevalence rate of FASD in the general population (e.g., Flannigan et al., 2018) tells us that professionals and service providers should be well versed in the range of manifestations that can result from prenatal alcohol exposure, and to actively screen for this potential in routine practice (Goh et al., 2008). For professionals and service providers, having a greater awareness and understanding of prenatal alcohol exposure can also help to inform service needs and goals, while providing unique insight into the individuals' compliance, motivation, and success within that service (Bertrand, Floyd, & Weber, 2005; Brown et al., 2018; Paley & O'Connor, 2009). As our findings suggest, it is also imperative that professionals and service providers consider the various psychosocial factors that commonly occur within this population, such as frequent changes in living environments and experienced trauma, when formulating service plans and setting expectations (Henry, Sloane, & Black-Pond, 2007; Streissguth et al., 2004; Zarnegar et al., 2016).

Beyond screening and assessment efforts, the management and intervention for individuals with FASD, and those with prenatal alcohol exposure who do not meet diagnostic criteria, also requires a multidisciplinary approach (e.g., Masotti et al., 2015). Our findings support that multiple service entities are required in the active management and care of children and youth with prenatal alcohol exposure in Northeastern Ontario. The various professionals and service providers within the region that may frequently be involved in this care include

occupational therapists' to address motor skills, sensory issues, and areas of adaptive behaviour impairment. Speech language pathologists' play an important role in addressing language and social communication needs. Psychologists and other mental health providers are also required for their expertise in mental health, as well as impairments in areas of cognitive functioning. In addition to these professionals, medical professionals may be frequently accessed for routine care, as well as physical impairments associated with prenatal alcohol exposure. Social workers may also provide case management and counselling services and specially trained FASD workers are highly warranted to provide individualized and informed supports.

Though the current study focused on the diagnostic outcomes within Northeastern Ontario, which subsequently inform service needs, these findings can also be useful in addressing the region's capacity to meet these demands. A previously identified lack of FASD specific supports, substantial wait lists, and poor knowledge among community members (Watson, Hayes, Coons et al., 2013), as well as limited training on FASD for health care professionals within the region (Coons, Watson, Yantzi, Lightfoot, & Larocque, 2017), together suggest that the region may be poorly equipped to offer quality services and resources to this population. Previously identified barriers with respect to the availability and accessibility of health care services more broadly in Northern Ontario (Al-Hamad & O'Gorman, 2015) likely further contribute to this issue, and underscores the need for greater research and policy development in the region.

In an effort to establish a collaborative multidisciplinary approach to managing FASD, professionals and service providers are encouraged to be open in their discourse and exchange of information amongst each other, while also being aware of the existing FASD-informed services within the region that can be offered to families (Bertrand et al., 2005). Given the difficulties

families may encounter with navigating and obtaining appropriate services (e.g. Pepper et al., 2018), professionals should seek to refer and connect families to available services as often as possible. Service providers should also inquire about other professionals involved in the individual's care and reflect this acknowledgment in any provided recommendations to further augment these additional areas of service. It is also known that individuals with FASD tend to do better when their environment is consistent, stable, and tailored to individualized needs (Paley & O'Connor, 2009; Streissguth et al., 2004). Therefore, service goals (e.g., what the individual wishes to gain from the service) and recommendations (e.g., how to apply strategies to different settings such as home, school, and community) should also recognize the various environments within which, an individual functions, and professionals should ensure transferability of service gains amongst these settings.

It would be particularly beneficial for service providers working with a child or youth with FASD to encourage the involvement of the educational institution throughout the service duration given an identified lack of knowledge regarding FASD in this setting (e.g., Pei, Job, Poth, & Atkinson, 2013). Furthermore, in Northeastern Ontario specifically, schools have been reported by families to be challenging in that they are often unaware of FASD, including strategies and approaches to effectively manage and educate students with the disorder (Watson, Hayes, Coons et al., 2013). In the current study, schools were not found to be active referral sources, which may imply a lack of knowledge, and the proportion of school suspensions/expulsions may also lend support to an inability to effectively manage and thus educate students with FASD. Moreover, providing tailored recommendations to school providers, including sharing information related to the individual's strengths, limitations, and areas of support need identified through the specified service may be particularly beneficial.

Professionals and service providers in the region may also benefit from greater knowledge and understanding of how to tangibly implement or modify service deliveries to ensure individuals with FASD benefit from their expertise. Past researchers have addressed various strategies to use when interacting with individuals with FASD to accommodate areas of weakness, which can be similarly extrapolated from the current study's findings. More specifically, choice of wording should be simple, clear, and to the point, and the use of close-ended questions as opposed to open-ended ones may provide greater and more meaningful responses (Huggins, Grant, O'Malley, & Streissguth, 2008). When outlining expectations, requests, or tasks, breaking them down into individual steps would be beneficial, while ensuring sufficient time is given for the processing of information (Coons, 2013; Kalberg & Buckley, 2007; Millians, 2015). For example, in an effort to accommodate working memory and executive functioning deficits, the use of repetition, rehearsal of information, and seeking confirmation of the individual's understanding can maximize outcomes (Huggins et al., 2008; Millians, 2015).

Environments in which services take place should be clear of any distractions to maintain attention (e.g., limit objects in the room; Kalberg & Buckley, 2007; Paley & O'Connor, 2009) and being mindful of attention as well as sensory needs may warrant appointments to be scheduled for shorter durations, frequent breaks to be given throughout, or other individualized modifications. An additional and important consideration for professionals and service providers to be cognizant of are the developmental needs of the individual with FASD. Individuals with FASD are often described as presenting younger than their stated age, with the gap between chronological and developmental age widening over time (Coons, 2013; Nash, Koren, & Rovet, 2011). This discrepancy is commonly seen in respect to the individual's comprehension of information, social maturity and skills, ability to think critically, and daily living skills (Malbin,

2005). Therefore, services may need to be modified based on this information to ensure that they are developmentally appropriate.

For mental health professionals specifically, routine screening for psychosocial factors and adverse outcomes may be particularly helpful in preventing future difficulties as well as to inform a therapeutic approach. As reported in the FASD literature and supported by our findings, the use of attachment-based and trauma-informed therapeutic models are commonly warranted with this population (e.g., Brown et al., 2018). For children with FASD, play or art-based approaches may also help with the expression of thoughts and feelings, particularly when language deficits are present (Gerteisen, 2008). Screening for, and following up on, behavioural problems is also highly suggested for mental health professionals (Tsang, Lucas, Olson, Pinto, & Elliott, 2016), given the strong association these have with adverse outcomes and difficulties later in life (Greenbaum et al., 2009; McLachlan & Rasmussen, 2018). Mental health professionals, and psychologists more specifically, should be acutely aware of the risk of suicidality among the population (O'Connor et al., 2019) and screen accordingly.

Additionally, it is important that psychologists' recognize the importance and emphasis on clinical judgment when it comes to assessing the intellectual functioning of individuals with FASD, understanding that cognitive deficits may not be best reflected or obtained using standardized measures (Brown et al., 2018). For example, clinical judgment may become particularly important when choosing assessment measures as well as during the interpretation of assessment findings when assessing an individual with FASD. When reviewing the FASD diagnostic guidelines (Cook et al., 2016), and the widespread neurodevelopmental impairment among individuals with FASD in the current study, it is clear that psychologists should ideally play a significant role in both the diagnosing and treatment of this population. Furthermore, it is

likely that psychologists may come into contact with families and caregivers of an individual with FASD who may be seeking support for previously identified feelings related to caregiver stress and burn out (e.g., Paley et al., 2006). In these instances, having an understanding of the spectrum of deficits and challenges associated with FASD can be beneficial to both the clinician and the client. While research in this area is lacking, previous researchers have reported limited knowledge pertaining to the diagnosis, intervention, and prevention of FASD among psychologists specifically (Wedding et al., 2007). Moreover, families caring for individuals' with FASD in the region have raised the issue of a lack of knowledge and support among professionals as a whole (Watson, Hayes, Coons et al., 2013). Therefore, efforts to increase the education and competency of psychologists in regards to FASD seem highly warranted.

The importance of keeping caregivers and families central in any management or intervention plan for individuals with FASD has been well established given their significant role in the support, consistency, and advocacy for the individual (Brown et al., 2018; Paley & O'Connor, 2009; Kalberg & Buckley, 2007; Zarnegar et al., 2016). As such, families should be given appropriate education on the disorder, provided effective strategies for dealing with problematic behaviour, and afforded services for their own well-being (Bertrand et al., 2005; Paley et al., 2006). Within rural and remote communities, accessible and cost-effective support resources may be particularly important, such as on-line, or remote access educational and support-based groups. Families should also be asked for their front line knowledge and experience caring for an individual with FASD (Coons et al., 2016), and this information should be actively incorporated into the development or modification of intervention methods to ensure they are appropriate, effective, and meaningful for individuals with FASD and their families.

Essentially, professionals and service providers should actively seek to form collaborative relationships with families, who understand the strengths and limitations of the individual best.

Clinical and Practical Implications for the Sudbury FASD Diagnostic Clinic

A final clinical implication that is important to discuss relates to the diagnostic clinic where individuals in our sample were assessed for FASD, and where all children and youth are referred within Northeastern Ontario. Though the requirement that prenatal alcohol exposure is confirmed prior to the FASD assessment being conducted is useful in ensuring a timely and efficient service, it can be seen as having significant repercussions for individuals where this confirmation cannot be ascertained. Essentially, it is possible that in some cases individuals with FASD are not diagnosed because prenatal alcohol exposure cannot be confirmed. Obtaining confirmation of prenatal alcohol exposure has been repeatedly identified as a significant barrier to the FASD diagnostic service, and is especially difficult for foster and adoptive families (Benz et al., 2009; Watson, Hayes, Coons et al., 2013). Consequently, without access to this service many individuals and families within the region are likely to be without contact to well needed services, and the difficulties the individual with suspected FASD and the family experiences are likely to worsen (e.g., Streissguth et al., 2004). The finding that children and youth in our sample who did not receive a diagnosis still presented with neurodevelopmental impairment and mental health concerns further emphasizes the importance of assessing all individuals suspected of having FASD in an effort to proactively identify and remediate difficulties.

Findings from the larger National Database project suggest that specific assessment procedures and adherence to the FASD diagnostic guidelines may differ across clinics in Canada (Temple, Cook, Unsworth, Rajani, & Mela, 2019). Reviewing the assessment process and

implementation of diagnostic guidelines at the Sudbury FASD Diagnostic Clinic offers unique and encouraging information for the region. More specifically, many of the standardized measures used at the Sudbury clinic (as outlined in Appendix B) align well with what is recommended by the diagnostic guidelines (Cook et al., 2016), as do the clinical cut offs to determine clinical impairment for each neurodevelopmental domain. A particular area of the assessment process where the Sudbury Diagnostic clinic demonstrates a strong adherence relates to affect regulation (i.e., one of the ten neurodevelopmental domains). While the diagnostic guidelines indicate that impairment in affect regulation can be supported by an individual meeting DSM-5 diagnostic criteria for several listed mood and anxiety related disorders, an emphasis is made on ensuring that the dysregulation is not better accounted for by additional factors, such as poor environmental circumstances (Cook et al., 2015). Compared to other participating clinics in the National Database project, the Sudbury clinic has been noted to identify impairment in affect regulation considerably less often (Cook, 2019). However, and as supported in our findings, a high proportion of children and youth presenting to the clinic have mental health concerns and have also experienced trauma, which makes this area of impairment difficult to thoroughly assess. Essentially, the team will not assign a “hit” for this domain unless it is explicitly clear that the impairment has been long term, and is best explained as being a result of prenatal alcohol exposure. Together, this “conservative” diagnostic approach the Sudbury Clinic employs ensures that individuals presenting at the clinic are receiving best practice assessments, and that alcohol is a causative factor to an individuals’ impairments and presentation.

Lastly, the 326 participants in the current study, which is reflective of all accessible patient charts that could be reviewed since the Sudbury diagnostic clinic’s establishment in 2011,

demonstrates a significant demand for this diagnostic service in Northeastern Ontario. In addition to the large number of children and youth who have been assessed, the clinic's waitlist and average time to be assessed is significant and continues to grow. Our findings provide evidence for the importance of continued, ongoing funding for the NEO Kids FASD clinic to support individuals and families within Northeastern Ontario communities. It is also important to acknowledge the challenges and stressors families seeking an FASD diagnosis experienced prior to the Sudbury clinic existing (Watson, Hayes, Coons et al., 2013), as well as the degree of impairment reported in our study, to demonstrate the relevance and priority of this service. Increased funding for the clinic could also further expand assessment capacity within the region, potentially allowing for individuals without confirmed prenatal alcohol exposure to undergo assessment.

Overall Conclusion

In conclusion, this thesis has provided insight into the profile of children and youth who present for an FASD assessment in Northeastern Ontario and has pointed to particular areas of impairment and service need for those who receive a diagnosis and those who do not. Such information is valuable for professionals in the region when working with individuals with FASD, and helps to promote FASD-informed practices. This information can also be used to increase the range and quality of support offered in the region. Finally, this thesis highlights the importance of conducting research in this area, addressing service needs, and informing where efforts are needed to ultimately improve the lives of individuals with FASD and their families in the region.

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Appendix A

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CanFASD DataformPreferred language/Langue de préférence: English Français

DEMOGRAPHIC INFORMATION AND PATIENT CHARACTERISTICS

Identification

Site ID _____

Country

-
- Canada
-
-
- Australia
-
-
- New Zealand
-
-
- United States
-
-
- United Kingdom
-
-
- France
-
-
- Other

Please specify

Province/Territory

-
- AB
-
-
- BC
-
-
- MB
-
-
- NB
-
-
- NS
-
-
- NL
-
-
- NWT
-
-
- NU
-
-
- ON
-
-
- QC
-
-
- SK
-
-
- YK

Year of Diagnosis _____

Type of assessment

-
- Initial Assessment
-
-
- Re-assessment
-
-
- Follow-up

Date of Referral

Month

-
- January
-
-
- February
-
-
- March
-
-
- April
-
-
- May
-
-
- June
-
-
- July
-
-
- August
-
-
- September
-
-
- October
-
-
- November
-
-
- December

Year _____

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Source of Referral

- Social Services Agency (e.g., Child and Family Services agency, community support agency)
 Medical Referral
 Education System (e.g., school, daycare)
 Legal System
 Self
 Family referral (e.g., biological, foster, adoptive parent)
 Other

Specify _____

Reason(s) for referral

Please check all that apply

- Behavioural issues
 Learning difficulties
 Difficulties with the law
 Developmental delays/delays to meet developmental milestones
 Adaptive living problems
 Confirmed prenatal alcohol exposure
 Social skills difficulties
 Self-regulation difficulties (feeding, sleeping, sensory)
 Reassessment
 Follow-up
 Establish eligibility for supports (e.g., financial or developmental support programs)
 Other

Please specify _____

Was a screening tool used for referral?

- No Yes

Which tool? _____

Who did the screen? _____

Date of Multi-disciplinary Assessment

Month

- January
 February
 March
 April
 May
 June
 July
 August
 September
 October
 November
 December

Year _____

Sex

- Male Female

Gender identity

- Male Female Other

Please specify _____

Date of Birth

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Month

- January
 February
 March
 April
 May
 June
 July
 August
 September
 October
 November
 December

Year

Which ethnic group(s) does this person most identify with?

- Caucasian
 Indigenous
 African American
 Latin American
 South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
 West Asian (e.g. Iranian, Afghan, etc.)
 Chinese
 Filipino
 Korean
 Japanese
 Southeast Asian (e.g. Vietnamese, Cambodia, Laotian, Thai, etc.)
 Arab
 Other
 Unknown

Specify

Current living situation

- Independent
 With biological mother
 With biological father
 With other family member(s)
 Foster care (non-family member)
 Adoptive parent(s)
 Group home
 Homeless
 In custody
 Other

Specify other family member(s)

Specify

Has a biological parent been diagnosed with FASD?

- No Yes Unknown

Has a sibling been diagnosed with FASD?

- No
 Yes
 Unknown
 Not applicable (no siblings)

ASSESSMENT OF PRENATAL ALCOHOL EXPOSURE

Prenatal alcohol exposure is:

- Absent (Confirmed)
 Present (Confirmed)
 Unconfirmed
 Unknown

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Please specify source, if known _____

Other prenatal exposures:

	Absent (Confirmed)	Present (Confirmed)	Unknown
Nicotine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opiates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marijuana	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cocaine/crack	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methamphetamine/speed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prescription medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Exposures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify _____

Other factors

Please check all that apply

- Post-natal trauma
 Attachment issues
 Sexual or physical abuse
 Other

Please specify _____

SENTINEL FACIAL FEATURES

Palpebral fissure norms used:

- Canadian norms
 Thomas
 Scandinavian
 Other

Please specify _____

Palpebral fissure length

- >-1 SD
 > -2 SD & < -1 SD
 < -2 SD

Philtrum smoothness

- 1
 2
 3
 4
 5

Score on lip-philtrum guide

Upper lip thinness

- 1
 2
 3
 4
 5

Score on lip-philtrum guide

Total number of sentinel facial features present

- 0
 1
 2
 3
 Inconclusive

NEUROBEHAVIOURAL ASSESSMENT

Brain Domain Assessment Results

Please indicate how the following brain domain was assessed

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	Not impaired	Impaired	Not Assessed
Motor skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuroanatomy/Neurophysiology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Academic achievement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Executive function including impulse control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Affect Regulation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adaptive behaviour, social skills, or social communication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Full scale IQ

Less than 70
 70
 71-85
 greater than 85
 Unable to calculate

Diagnosis

FASD with sentinel facial features
 FASD without sentinel facial features
 At risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure
 No FASD Diagnosis

Do you use another diagnostic schema to record information (i.e. 4-digit code)?

No Yes

Please provide the 4-digit diagnostic code

Other associated features

Please check all that apply

Sleep problems
 Sensory sensitives
 Sensory processing
 Trauma
 Slower processing speed
 Gender identity
 Other

Please specify

Other diagnoses

Note: Assessment did not have to occur at this clinic.

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	No (Assessed but not diagnosed)	Yes (Assessed and diagnosed)	Not assessed
Congenital malformations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intellectual disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ADD/ADHD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attachment disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Developmental coordination disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Language disorder/impairment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Auditory deficit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visual deficit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tourette's	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autism Spectrum Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bipolar disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conduct disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mood disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obsessive compulsive disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personality disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PTSD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Schizophrenia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Substance abuse disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suicide attempt(s)/Ideation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify

MEDICAL HEALTH HISTORY

Growth restriction

No Yes

Please specify

Neurological conditions

No Yes

Please specify

Mental health

No Yes

Please specify

Head and neck issues

No Yes

Please specify

Cardiovascular conditions

No Yes

Please specify

Respiratory system

No Yes

Please specify

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Endocrinological conditions No Yes
 Please specify _____

Musculoskeletal No Yes
 Please specify _____

Infectious diseases No Yes
 Please specify _____

Other No Yes
 Please specify _____

MEDICATION

	No	Yes
Omega-3	<input type="radio"/>	<input type="radio"/>
Choline	<input type="radio"/>	<input type="radio"/>
Glutamine	<input type="radio"/>	<input type="radio"/>
Aripiprazole	<input type="radio"/>	<input type="radio"/>
Vortioxetine	<input type="radio"/>	<input type="radio"/>
Minocycline	<input type="radio"/>	<input type="radio"/>
Bupropion	<input type="radio"/>	<input type="radio"/>
Buspirone	<input type="radio"/>	<input type="radio"/>
Clozapine	<input type="radio"/>	<input type="radio"/>
Melatonin	<input type="radio"/>	<input type="radio"/>

Please list all other current medications

Stimulants

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Anti-depressants

Medication 1: _____

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- Medication 2: _____
- Medication 3: _____
- Medication 4: _____
- Medication 5: _____
- Medication 6: _____
- Medication 7: _____
- Medication 8: _____
- Medication 9: _____
- Medication 10: _____

Anti-psychotics

- Medication 1: _____
- Medication 2: _____
- Medication 3: _____
- Medication 4: _____
- Medication 5: _____
- Medication 6: _____
- Medication 7: _____
- Medication 8: _____
- Medication 9: _____
- Medication 10: _____

Birth Control Pills

- Medication 1: _____
- Medication 2: _____
- Medication 3: _____
- Medication 4: _____
- Medication 5: _____
- Medication 6: _____
- Medication 7: _____
- Medication 8: _____
- Medication 9: _____
- Medication 10: _____

Hormone replacement therapy

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- Medication 1: _____
- Medication 2: _____
- Medication 3: _____
- Medication 4: _____
- Medication 5: _____
- Medication 6: _____
- Medication 7: _____
- Medication 8: _____
- Medication 9: _____
- Medication 10: _____

Anti-hypertensives

- Medication 1: _____
- Medication 2: _____
- Medication 3: _____
- Medication 4: _____
- Medication 5: _____
- Medication 6: _____
- Medication 7: _____
- Medication 8: _____
- Medication 9: _____
- Medication 10: _____

Anti-convulsants

- Medication 1: _____
- Medication 2: _____
- Medication 3: _____
- Medication 4: _____
- Medication 5: _____
- Medication 6: _____
- Medication 7: _____
- Medication 8: _____
- Medication 9: _____
- Medication 10: _____

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Other

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Are any of the following substances currently being used/misused?

	No	Yes	Unknown
Alcohol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tobacco	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marijuana	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opiates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Solvents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Crack/Cocaine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify _____

Are any of the following substance use/misuse treatments currently being accessed?

	No	Yes	Unknown
Alcohol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tobacco	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marijuana	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify _____

Are any of the following currently being experienced?

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	No	Yes	Unknown	To be followed up after clinic
Teachers assistants prior to diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School expulsion/suspension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Needs help living on own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Needs assisted or sheltered housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal problems: Victim	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal problems: Offender	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Custody issues/family court	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Special courts jail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regular courts jail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incarcerated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Which of the following recommendations were made?

	No	Yes	Service not available
Coaching	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support (individual or group)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication strategies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
FASD assessment/early intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling or individual therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Couple/family counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Substance abuse counselling/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elder abuse intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	No	Yes	Service not available
Child protection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spousal abuse intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Income support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Food bank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency housing/shelter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daycare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Guardianship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Power of Attorney	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal directive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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	No	Yes	Service not available
Legal aid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services for civil court issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services for family court issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech and language pathologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behaviour Therapy services (ABA, IBI, and other BT supports)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication/psychopharmacology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accommodations/adaptation in environment, expectations, supports used, or routine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anticipatory Guidance/Prevention: for the purpose of increasing awareness and/or decreasing risk of potential future problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety: Precautions to be taken or specific measures to deal with safety concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reassessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other substitute decision-making options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other legal services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other medical referral	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix B

Standardized Measures for Assessing Neurodevelopmental Domains used at the Sudbury FASD Diagnostic Clinic

Neurodevelopmental Domain	Assessment Tool
Motor Skills	The Peabody Developmental Motor Scale (Fine Motor), 2 nd Edition (PDMS-2)
	Beery-Buktenica Developmental Test of Visual-Motor Integration 6 th Edition (VMI)
	Bruininks-Oseretsky Test of Motor Proficiency- 2 nd Edition (BOT-2)
	Beery VMI Developmental Test of Motor Coordination- 6 th edition (MC)
Neuroanatomy/ Neurophysiology	Nurse practitioner assessment
Cognition	Wechsler Preschool and Primary Scale of Intelligence- Fourth Edition (WPPSI- IV)
	Wechsler Intelligence Scale for Children- Fourth Edition (WISC-IV)
	Wechsler Adult Intelligence Scale- Fourth Edition (WAIS-IV)
Language	Clinical Evaluation of Language Fundamentals (CELF P-2 & 5).
	Montgomery Assessment of Vocabulary Acquisition- Expressive and Receptive Vocabulary (MAVA)
	Comprehensive Assessment of Spoken Language (CASL)
Academic Achievement	Wechsler Individual Achievement Test- Third Edition (WIAT- III)
Memory	Wide Range Assessment of Memory and Learning, Second Edition (WRAML-2)
	Children's Memory Scale (CMS)

Attention	Conner's Continuous Performance Test, Third Edition (CPT-3) The Behavior Assessment System for Children, Third Edition (BASC-3)
Executive Functions	A Developmental Neuropsychological Assessment (NEPSY- II) Working Memory Scales on WAIS-IV or WRAML-2 Test of Problem Solving Elementary 3 rd Edition (TOPS-3-Elementary)
Affect Regulation	As per client history (Dx of anxiety/ and or depression disorder)
Adaptive Behaviour, Social Skills, Social Communication	Adaptive Behaviour Assessment System- Third Edition (ABAS-3) Social Language Development Test- Elementary/ Adolescent (SLDT- E/A)

Note: Measures used are dependent on client age.

Appendix C

Laurentian University Research Ethics Board Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
 Research Ethics Board Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL <input type="checkbox"/> New <input type="checkbox"/> Modifications to project <input type="checkbox"/> Time extension <input type="checkbox"/>	
Name of Principal Investigator and School/department	Jessica Burns, Psychology, Supervisors Shelley Watson, Kelly Harding, Psychology
Title of Project	Fetal Alcohol Spectrum Disorder: Diagnostic outcomes in Northeastern Ontario
REB file number	6014984
Date of original approval of project	October 3 rd , 2018
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on: (You may request an extension)	October 3 rd , 2019
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PhD, Chair, Laurentian University Research Ethics Board