

RISK AND PROTECTIVE FACTORS FOR CRIMINALITY AMONG ADULTS WITH FASD

by

Elisa Radford-Paz

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### APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Shelley Watson  
(Supervisor/Directrice de thèse)

Dr. Michel Larivière  
(Committee member/Membre du comité)

Dr. Adèle Robinson  
(Committee member/Membre du comité)

Dr. Voula Marinos  
(External Examiner/Examinatrice externe)

Approved for the School of Graduate Studies  
Approuvé pour l'École des études supérieures  
Dr. David Lesbarrères  
M. David Lesbarrères  
Director, School of Graduate Studies  
Directeur, École des études supérieures

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## **Abstract**

This research explored the risk and protective factors associated with criminality among adults with Fetal Alcohol Spectrum Disorder (FASD). While previous research has focused on identifying the factors that contribute to legal issues, there is a paucity of research on the protective factors that may lead to more positive outcomes for adults with FASD. The first paper examined the methodological issues encountered while conducting a mixed methods study on the experience of offenders and non-offenders with FASD. Difficulties with participant recruitment, the sample size, the terminology employed, and the appropriateness of psychometric measures were significant challenges that emerged during the research project. The second paper was a qualitative study that investigated the experience of adults with prenatal alcohol exposure and their families to determine the risk and protective factors for criminality. Families reported that neurobehavioural impairments such as difficulty with self-regulation and social skills deficits, combined with environmental demands that exceeded the capabilities of the individual with FASD, were important contributors to criminality. However, structure and supervision, education and employment, social and financial support, and positive peer influence were found to mitigate the risk of criminal behavior among adults with FASD. The findings from this thesis highlight the importance of including families in the research process as well as the need to have more family-centered services.

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## CHAPTER ONE. INTRODUCTION

The teratogenic effects of alcohol have become an important health and social issue in Canada, propagating research into the lifelong impairments caused by prenatal alcohol exposure (Chudley et al., 2005). Jones and Smith (1973) were the first to coin the term Fetal Alcohol Syndrome (FAS) as a clinical description of the morphological anomalies and developmental delays associated with gestational alcohol exposure. As research continued to emerge, it became apparent that the teratogenic effects of alcohol varied as a function of biological and environmental factors, making it a multifarious disability that is not always manifested through visible, physical characteristics (Astley & Clarren, 2000). As a result, the umbrella term Fetal Alcohol Spectrum Disorder (FASD) was employed as a more accurate description of the continuum of physical, cognitive, and behavioural effects caused by prenatal alcohol exposure (Chudley et al., 2005).

In addition to the permanent impairments caused by exposure to alcohol prenatally, individuals with FASD are susceptible to adverse life outcomes. The interaction between biological and environmental factors may lead to unpropitious developmental outcomes called secondary disabilities (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Streissguth, Barr, Kogan, & Bookstein, 1997). Streissguth and colleagues (1997) delineated the most common secondary disabilities in FASD, which included mental health disorders, disrupted school experience, legal trouble, confinement, inappropriate sexual behaviour, and problems related to the use of alcohol and drugs. Although secondary disabilities can present considerable hardships in the lives of individuals with FASD, there is a paucity of systematic research examining criminality among individuals with FASD in the context of well-established theories of criminal conduct (Verbrugge, 2003). The dearth of research on this important topic is surprising given that an

estimated 60% of individuals with FASD will experience legal problems (Streissguth et al., 2004). Furthermore, most studies have focused on the permanent disabilities that are related to neurobehavioural deficits yet little attention has been directed to the broader environmental and familial factors. The lack of understanding of the risk and protective factors associated with criminality in FASD has important implications for the interventions used within the criminal justice system. Thus, the following presents a summary of research on the risk and protective factors associated with criminal behaviour among individuals with FASD.

### **Sequelae of Prenatal Alcohol Exposure**

Although some early writings alluded to the knowledge of the adverse effects of prenatal alcohol exposure (Lamache, 1967; Lemoine, Harousseau, Borteryu, & Menuet, 1968; Sullivan, 1899), Jones and colleagues (1973) were the first to coin the term FAS as a reference to the clinical description of the physical and developmental anomalies associated with the teratogenic effects of alcohol (Jones & Smith, 1973; Jones, Smith, Ulleland, & Streissguth, 1973). In particular, they found that prenatal alcohol exposure affected three main areas of development: facial morphology (i.e., small palpebral fissures, flat midface, short nose, indistinct philtrum, and a thin upper lip), growth (i.e., birth weight and/or height at or below the 10<sup>th</sup> percentile, or disproportionately low height to weight ratio), and the central nervous system (i.e., structural abnormalities in the brain, and neurological hard and soft signs; Jones & Smith, 1973; Sokol & Clarren, 1989).

As research sought to identify the pathognomonic characteristics of FAS, subsequent studies on the mechanisms by which alcohol affects the developing fetus revealed a much more complex system (Riley, McGee, & Sowell, 2004). Alcohol reaches the fetus' blood by way of

the placental barrier, a semi-permeable layer of tissue that protects the fetus from some (but not all) substrates present in the mother's blood. Prenatal exposure to alcohol during gestation can interfere with the development of tissues and organs, particularly during critical periods of development (Coles, 1994; Schneider, Moore, Kraemer, Roberts, & DeJesus, 2002). For example, exposure to alcohol in the first trimester can cause craniofacial malformations (Kotch & Sulik, 1992). Furthermore, it has been suggested that structures such as the hippocampus, cerebellum, and prefrontal cortex are most vulnerable to exposure to alcohol in the third trimester (Coles et al., 1991; Livy, Miller, Maier, & West, 2003). In contrast with other organs that have a more discrete period of development, the central nervous system develops throughout gestation and can be affected by alcohol at any point even in the absence of facial and physical abnormalities, rendering FASD an "invisible disability" (Bertrand et al., 2004; Guerri, 1998).

In addition to time of exposure, other factors such as individual differences in the tolerance of alcohol, malnutrition during pregnancy, and concurrent exposure to other intoxicants can affect the developing fetus (Astley & Clarren, 2000). Furthermore, the quantity of alcohol and number of exposures that lead to FAS are unknown (Streissguth, Barr, Sampson, & Bookstein, 1994). While the deleterious effects of binge drinking on prenatal development have been well-documented (Sampson, Streissguth, Barr, & Bookstein, 1989; Streissguth et al., 2004), social drinking consisting of less than two drinks per day has also been associated with adverse developmental outcomes (Chen, 2012; Irner, 2012; Olson et al., 1997; Sood et al., 2001). Taken together, these findings suggest that prenatal alcohol exposure is multifaceted in how it presents from one individual to another, and that neurocognitive impairments may be present even in the absence of physical indicators (Connor & Streissguth, 1996).

To account for the high degree of variability in the phenotype resulting from prenatal alcohol exposure, the umbrella term FASD is employed to describe the continuum of physical, cognitive, and behavioural effects caused by maternal alcohol consumption during pregnancy. It is estimated that the prevalence of FASD in Canada is 2 to 5 in 100 children (May et al., 2009), making it the leading preventable cause of developmental and intellectual disabilities in both Canada and the United States (O’Leary et al., 2012). Although FASD is not a diagnostic term, it encompasses several diagnostic categories including FAS, partial FAS, and alcohol-related neurodevelopmental disorder (ARND). While the labels Fetal Alcohol Effects (FAE) and alcohol-related birth defects (ARBD) are no longer used as diagnostic terms, they were previously employed to denote congenital abnormalities caused by prenatal alcohol exposure in cases where central nervous system damage is not accompanied by the characteristic facial dysmorphism (Sokol & Clarren, 1989). In Canada, a diagnosis is made according to the 4-digit Diagnostic Code proposed by Astley and Clarren (2000). This diagnostic code employs a four-point Likert scale to assess the magnitude of four main diagnostic features of FASD: growth deficiency, the FAS facial phenotype, central nervous system damage or dysfunction, and gestational alcohol exposure (Astley & Clarren, 2000).

### **Primary and Secondary Disabilities**

Exposure to alcohol prenatally interferes with neurogenesis and leads to structural and functional abnormalities within the brain (Sowell et al., 2001a; Sowell et al., 2001b). Most notably, prenatal exposure to alcohol has been associated with microcephaly, agenesis of the corpus callosum and anterior commissure, as well as anomalies in the cerebellum, prefrontal cortex, brain stem, basal ganglia, and hippocampus (Guerra, Bazinet & Riley, 2009). The cognitive and neurobehavioural impairments that result from brain dysfunction are called

primary disabilities (Streissguth et al., 1997). While the extent of the primary disabilities present in FASD is still in large part unknown, it is well documented that individuals with FASD have deficits in cognitive functioning, executive functions (EF), visuospatial abilities, attention, memory, language, motor skills, academic achievement, adaptive behaviour and social skills (for a review, see Mattson, Crocker, & Nguyen, 2011). These primary disabilities, which are present since birth, can predispose individuals with FASD to vulnerabilities and can lead to the development of secondary disabilities (Clark et al., 2004).

Secondary disabilities result from the interaction between inherent cognitive impairments, problems with mental health, and adverse environment (Clark et al., 2004). Arising from primary disabilities, secondary disabilities are not permanent and may be improved by remedial interventions, making them important from a preventative perspective (Streissguth et al., 1997). Regrettably, many individuals with FASD are exposed to significant life stressors from an early age. Many are apprehended from their families of origin and placed in foster or adoptive homes due to adverse home environments. Furthermore, they are often vulnerable to physical, emotional, and sexual abuse (Roach & Bailey, 2009; Streissguth et al., 1997). The combination of primary disabilities and environmental risk factors often lead to deleterious life outcomes for individuals with FASD.

Streissguth and colleagues (2004) conducted a large-sample study to identify secondary disabilities in children, adolescents, and adults (ages ranged from 6-51 years) with FAS or FAE. Using the responses gathered through the Life History Interview, which was administered to parents or guardians of the participants, the authors identified the life span prevalence of six common secondary disabilities: mental health problems (90%), disrupted school experience (61%), legal trouble (60%), confinement (50%), recurrent inappropriate sexual conduct (49%),

and problems related to the use of alcohol and drugs (35%). Similar findings were also reported in a Canadian sample of adults with FASD (Clark et al., 2004). It should be noted that these secondary disabilities are not mutually exclusive; rather, they can occur together. For instance, some secondary disabilities, such as inappropriate sexual behaviour and the use of alcohol and drugs, can lead to trouble with the law. Furthermore, the implication of criminality extends to confinement, as convictions of a crime can result in incarceration (Clark et al., 2004). Thus, secondary disabilities can present considerable adversities in the lives of individuals with FASD.

Building on the existing body of research on primary and secondary disabilities, Malbin, Boulding, and Brooks (2010) suggested that the challenging behaviours associated with FASD are neurobehavioural in nature. As a result, the severity of the secondary disabilities is dependent on the degree of discord between the neurobehavioural deficits and the environmental demands imposed on an individual. In accordance with the primary disabilities described by Streissguth and colleagues (1997), primary characteristics were described as behaviours that are more clearly linked with central nervous system dysfunction, such as impairments in cognitive functioning, EF, and memory. Secondary characteristics, including fatigue, frustration, aggression, and social isolation, are a set of behaviours that develop over time when the demands placed on an individual outweigh their capabilities. Tertiary characteristics are the final result of the long-term incompatibility between an individual's abilities and their environment, such as trouble with the law and incarceration. By employing a ternary classification system that describes how adverse life outcomes evolve over time as an interaction between biological predispositions and environmental factors, preventative strategies can be developed to identify and address the early signs that an individual with FASD may be at risk for secondary disabilities (Malbin et al., 2010).

## **Criminality in FASD**

Among the secondary disabilities present in FASD, trouble with the law is one of the most problematic. In fact, an estimated 60% of individuals with FASD will experience legal problems, with adolescents and adults with an IQ greater than 70 being at increased risk for criminality (Streissguth et al., 2004). Furthermore, the number of individuals with FASD in the Canadian corrections system is 10 to 40 times higher than the worldwide prevalence (Fast, Conry, & Loock, 1999). The prevalence rates reported suggest that FASD is often managed within the context of the criminal justice system rather than other sectors, such as the health care system. Indeed, the breadth of publications on the jurisprudence of FASD comes from judges and lawyers (Roach & Bailey, 2009). Even so, the majority of the published information on FASD and criminality is based on anecdotal accounts and descriptive studies (Verbrugge, 2003).

Despite the staggering finding that 60% of individuals with FASD will have some trouble with the law, few studies have looked at the prevalence of FASD in the legal system. One study examined the prevalence of FASD within a population of remanded youth in British Columbia, Canada (Fast et al., 1999). All juvenile delinquents mandated to a psychiatric or psychological assessment in a 1-year period were evaluated. Of the 287 participants assessed, 23.3% had FASD. However, of the individuals diagnosed with FASD, only 1% met criteria for FAS while the remainder were diagnosed with ARND (Fast et al., 1999). It is important to note that the estimates provided by Fast and colleagues (1999) are based solely on individuals who are incarcerated, and fail to take into account those who have faced legal problems but may not have been imprisoned. Thus, although the study provides a good estimate of the prevalence of FASD in correctional settings, it is believed that the prevalence rate for criminality in youth with FASD is likely to be higher. A systematic review of studies on the Canadian prevalence of FASD in the

criminal justice system found that youth with FASD were 19 times more likely to be incarcerated compared to the general population (Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011).

Although little is known about the prevalence of FASD in incarcerated adults, it is widely believed that many individuals involved in the criminal justice system have been exposed to alcohol prenatally but have never received a formal diagnosis. In a survey conducted in the United States, only one individual of the 3.08 million inmates surveyed had been diagnosed with FAS (Burd, Selfridge, Klug, & Bakko, 2004). Similarly, a survey of Canadian correctional services found that only 13 inmates had an actual diagnosis of FAS in a sample of 148,979 offenders (Burd, Selfridge, Klug, & Juelson, 2003). Given that other studies have shown high rates of criminality and incarceration in individuals with FASD, the authors concluded that there is a significant need to improve screening for FAS (Burd et al., 2003). A limitation of the studies examining the prevalence of FASD in correction systems is that they only looked at FAS and other diagnostic classifications such as ARND and ARBD, which refer to individuals who have the behavioural and cognitive features but none of the physical characteristics, were not taken into account. Previous research found higher rates of criminality among individuals with FAE than those diagnosed with FAS (Streissguth et al., 1997). In part, this discrepancy has been attributed to the fact that individuals without the facial characteristics are less likely to receive an early diagnosis (or a diagnosis at all), and are therefore less likely to have access to supports and interventions (Olson, Jirikowic, Kartin, & Astley, 2007).

Despite the marked need for FASD screening in adult offenders, there are some significant challenges that make it difficult to obtain a diagnosis in adulthood. First, some of the physical characteristics associated with FASD such as facial dysmorphology or growth deficits can dissipate with age (Chudley et al., 2005). Second, only 20% of individuals with FASD

remained in the care of their biological mother (Astley, Bailey, Talbot, & Clarren, 2000; Streissguth et al., 2004), and it is therefore difficult to confirm maternal alcohol consumption. Finally, the adverse life outcomes to which individuals with FASD are exposed throughout their lifetime, including being exposed to violence and having multiple households, contribute to the complexity of diagnosing FASD in adulthood (Burd, Fast, Conry, & Williams, 2010). The experience of multiple traumatic events can yield similar effects as prenatal alcohol exposure, such as emotional dysregulation, cognitive impairments, and social deficits (Henry, Sloane, & Black-Pond, 2007). Without a comprehensive history of the individual, some of the impairments found in adult offenders may be attributed to trauma and an assessment of FASD may not be conducted.

Research has also focused on identifying the specific criminal activities in which individuals with FASD engaged. Streissguth and colleagues (2004) delineated the types of crimes most frequently perpetrated by individuals with FASD. They found that the first instance of documented criminal behaviour was typically related to shoplifting (Streissguth et al., 2004). In general, approximately 45% of criminal acts involved crimes against persons, including shoplifting or theft (36%), assaults (17%), burglary (15%), and domestic violence (15%). In a separate study, it was found that sexual misconduct accounted for approximately 13% of crimes, with males being more likely to be reported for inappropriate sexual behaviour than females (LaDue, Streissguth, & Randels, 1992). Notwithstanding, offenders with FASD typically exhibit a pattern of repeated, non-violent offences (Chudley, Kilgour, Cranston, & Edwards, 2007).

Contributing to the likelihood of recidivism is the difficulty individuals with FASD face in terms of complying with court orders and parole conditions (Chudley et al., 2007). Sentencing typically includes conditions such as attending appointments in a timely manner, participating in

cognitive and/or behavioural therapy, and complying with restrictions such as avoiding specific places or individuals. However, individuals with FASD struggle with cause and effect reasoning, time concepts, generalizing skills from one environment to another, and cognitive-based treatment (Brown, Connor, & Adler, 2012; Malbin, 2004; Mela & Luther, 2013). The neurocognitive deficits inherent to FASD are incompatible with the expectations outlined in court-mandated condition; thus, individuals with FASD are likely to violate the terms of the sentence and are therefore often considered to be “repeat offenders” by the court (Mela & Luther, 2013).

Beyond the social implications of criminality, the high rate of criminality among individuals with FASD has a significant economic impact. The annual cost of FASD in Canada is estimated to be \$344 million (Stade, Ungar, Stevens, Beyen, & Koren, 2007). However, these estimates are derived primarily from expenditures within health care, mental health, and education sectors and are based on individuals 21 years of age or younger (Nash et al., 2006; Stade et al., 2007). Furthermore, they do not adequately account for costs related to incarcerations, loss of productivity, and poor quality of life (Nash et al., 2006). Stade and colleagues (2007) suggest that the average lifetime cost of caring for an individual with FAS is \$1 million, indicating that for this diagnosis alone there is an associated annual cost of approximately \$4 billion across all systems. Popova, Lange, Burd and Rehm (2012) estimated that the economic burden of FAS on the health care sector alone from 2008 to 2009 was \$6.7 million. The true economic impact of FASD may therefore be difficult to ascertain; however, given the high incidence rate of individuals with FASD who are involved with the criminal justice system and that individuals with FAS account for only a small proportion of those individuals, it is likely that the economic impact of FASD is much higher than estimates

provided in the literature. Another limitation is the lack of research comparing the economic impact of FASD to the financial cost associated with other medical conditions or the general population (Popova, Lange, Burd, & Rehm, 2013). A Canadian study found that in the child welfare system, the average daily cost for child maintenance and special need services for a youth with FASD is 20% higher than the same care for an individual without FASD (Fuchs, Burnside, Marchenski, Mudry, & De Riviere, 2008). Despite the lack of data on the economic burden of FASD in relation to the general population, the available literature suggests that individuals with FASD require services from multiple systems, and that they require these services for longer than the general population (Popova et al., 2013). Thus, it is undeniably an important issue that needs to be addressed. Despite the importance of the problem, there is a paucity of systematic research that examines the factors that increase the likelihood that an individual with FASD will experience problems with the law.

### **Neurobehavioural Theory of Criminality**

Given the high incidence of criminality among adolescents and adults with FASD (Fast et al., 1999), several hypotheses have been proposed to explain criminality in individuals with prenatal alcohol exposure. One of the most widely accepted theories posits that delinquent behaviour is associated with neuropsychological deficits such as impulsivity and difficulty anticipating consequences (Malbin et al., 2010; Rasmussen & Wyper, 2007). The role of EF (i.e., planning, attentional flexibility, inhibitory control, and problem-solving) in self-regulation processes (i.e., the ability to regulate emotions, irrational thoughts, and strong urges) has been at the heart of many studies trying to explain maladaptive behaviour in FASD (Brown et al., 2012; Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998). As Brown and colleagues (2012) argue, “adaptive and social functioning relies on underlying executive skills, which control the

processing and integration of information and, ultimately, self-regulation” (pp. 770-771). More specifically, this relationship is attributed to inhibitory behaviour, a key component of self-regulation and EF (Marton, Wiener, Rogers, Moore, & Tannock, 2009; Rhoades, Greenberg, & Domitrovich, 2009). Thus, the neurobehavioural model is predicated on the idea that neuropsychological deficits lead to maladaptive behaviour. For example, deficits in EF may hinder the ability to engage in cause-effect reasoning, regulate emotions, learn from past mistakes, and adapt to social situations. These impairments, in turn, may increase the likelihood that an individual will face legal problems (Moore & Green, 2004; Streissguth, 1997).

Malbin and colleagues (2010) proposed a neurobehavioural model to explain the emergence of secondary disabilities, including criminality, as a consequence of the underlying central nervous system dysfunction caused by prenatal alcohol exposure. According to this model, primary characteristics develop into secondary and then tertiary characteristics as a result of a poor fit between the individual’s abilities and their environment. Whereas traditional models of criminality seek to identify the problematic behaviours (e.g., aggressive outbursts, lying, and defiance) and alter them through cognitive and behavioural treatment, the neurobehavioural model reframes challenging behaviours as manifestations of underlying deficits. In other words, behaviour such as aggression is not seen as willful or malicious, but rather as a sign that the demands placed on an individual outweigh their capabilities. Underlying deficits such as emotional dysregulation, impulsivity, and difficulty with language make it difficult for individuals with FASD to communicate their distress in a way that is consistent with societal standards that emphasize the need to resolve conflict verbally. In light of the impairments, distress may be manifested as aggression. By reframing the challenging behaviours associated

with FASD, interventions can be developed to accommodate the needs of the individual instead of focusing on the cognitive component (Malbin et al., 2010).

### **Executive Functioning in FASD**

Executive functions are a set of higher order cognitive abilities mediated by the frontal and prefrontal cortices that are implicated in purposeful, goal-directed behaviour (Anderson, 1998). Cognitive-based measures of EF, sometimes referred to as cool EF, are associated with the dorsolateral prefrontal cortex (Koditwakku, Kalberg, & May, 2001; Zelazo, Müller, Frye, & Marcovitch, 2003) and have been identified as a core deficit of FASD (Rasmussen, 2005). In particular, it has been well established that individuals with FASD have difficulty with cognitive flexibility or “set-shifting” (e.g., Rasmussen & Bisanz, 2009), response inhibition (e.g., Connor, Sampson, Bookstein, Barr, & Streissguth, 2000), planning and strategy use (e.g., Mattson, Goodman, Caine, Delis, & Riley, 1999), and attention (e.g., Green et al., 2009). Even when compared to other developmental disabilities such as Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder, and Traumatic Brain Injury, individuals with FASD show considerably greater deficits in EF (Anderson, Anderson, Northam, Jacobs, & Mikiewicz, 2002; Gioia, Isquith, Kenworthy, & Barton, 2002). There is extensive research that indicates that there is no relationship between the extent of neuropsychological deficits and the presence of the characteristic facial phenotype (Connor et al., 2000; Mattson, Riley, Gramling, Delis, & Jones, 1998; Rasmussen, 2005; Schonfeld, Mattson, Lang, Delis, & Riley, 2006a). Furthermore, neuropsychological deficits in FASD are greater than would be expected even when IQ is taken into account (Connor et al., 2000; Kerns, Don, Mateer, & Streissguth, 1997; Noland et al., 2003; Olson et al., 1998).

More recently, there has been increased interest in hot EF, a component of EF that is involved in the regulation of motivated and emotional behaviour (Zelazo et al., 2003). Unlike its cognitive counterpart, these actions are presumed to be mediated by the orbitofrontal cortex and are contingent on past rewards and punishment (Kodituwakku et al., 2001). To the author's knowledge, only two studies have investigated hot EF in individuals exposed to alcohol prenatally. In one study employing a modified version of the Visual Discrimination Reversal Test, participants were asked to respond differentially to rewarding ("winning") and non-rewarding ("losing") images. Positive, reinforcing feedback was presented for correct responses while negative feedback was given for incorrect responses. Once the participants answered 9 out of 10 blocks correctly, the reinforcing contingencies were suddenly reversed to produce an extinction condition. Children and adolescents with prenatal alcohol exposure showed greater impairments in emotional set-shifting when compared to a typically developing control group, even when controlling for conceptual set-shifting (a cognitive ability) and IQ. The findings from this study support the notion of two separate EF systems; one that is related to cognitive abilities and another that is associated with emotion-related EF (Kodituwakku et al., 2001).

In the same study, the authors investigated whether deficits in cognitive and emotional components of EF could accurately predict behavioural problems in children and adolescents prenatally exposed to alcohol. In addition to the aforementioned task of emotion-related EF, participants were administered the Wisconsin Card Sorting Test (WCST) to assess cognitive-based EF. In addition, parents completed the Personal Behavior Checklist - 36 and the Children's Executive Functioning Inventory, two questionnaires used to measure behavioural problems in children and adolescents. As expected, parental reports identified more behavioural problems in children exposed to alcohol prenatally than parents of typically developing children.

Furthermore, it was found the behavioural problems were accurately predicted by the number of perseverative errors on the WCST, as well as the number of omission errors and variability in extinction. As a result, it was concluded that individuals with FASD have deficits in both cognitive and emotional EF, and that both types of impairments were predictive of subsequent behavioural problems (Kodituwakku et al., 2001).

A more recent study compared hot EF in children with FASD and typically-developing controls (Kully-Martens, Treit, Pei, & Rasmussen, 2013). Participants were asked to complete the Iowa Gambling Task, which assesses components of hot EF such as decision-making and risk taking. Compared to the control group, children with FASD performed more poorly on the Iowa Gambling Task. In particular, they showed greater difficulty with cognitive flexibility, response inhibition, learning from previous experience through negative consequences, and employing strategies that lead to long-term rewards. While it is not possible to isolate the effects of hot EF from components of cool EF such as working memory and attention, the findings from this study may provide some insight on the underlying factors that interfere with the ability to learn from past experience, inhibit impulsive responses, and develop adaptive behaviour (Kully-Martens et al., 2013). The deficits in hot EF found in FASD are consistent with the neurobehavioural theoretical model, which posits that the inability to inhibit behaviour and self-regulate is associated with impairments in adaptive behaviour in FASD.

### **Adaptive and Social Functioning in FASD**

There is wealth of research detailing the impairments in adaptive and social functioning that are often found in FASD. Adaptive behaviours are skills relating to daily living, communication, and social interactions. According to the Diagnostic and Statistical Manual of

Mental Disorders (5<sup>th</sup> ed.; DSM-5; American Psychiatric Association, 2013), individuals with deficits in adaptive functioning “fail to meet standards for personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning and personal independence at home or in community settings” (American Psychiatric Association, 2013, p. 31). In particular, the Vineland Adaptive Behaviour Scales (VABS; Sparrow, Cicchetti, & Balla, 2005) have been widely used to assess daily functioning in individuals with FASD. In several studies using the VABS, individuals with FASD were shown to have impaired daily functioning in all domains of the VABS, namely Communication, Daily Living Skills, Socialization and Maladaptive Behavior (Olson et al., 1998; LaDue et al., 1992; Thomas et al., 1998; Whaley, O’Connor, & Gunderson, 2001).

In order to account for other variables that may cause impairments in adaptive behaviour, researchers have employed methodologies that allowed them to control for the effects of additional factors that may contribute to maladaptive behaviour. Deficits in adaptive behaviour were found in individuals with FASD, even when controlling for IQ (Carr et al., 2010, Olson et al., 1998; Whaley et al., 2001), socio-economic status (Thomas et al., 1998), and other developmental influences such as prenatal exposure to other intoxicants and aspects of the environment from childhood to adolescence (Olson et al., 1997). Although deficits in adaptive behaviour have been shown to be widespread (Carr, Agnihotri, & Keightley, 2010; Jirikowic, Kartin, & Olson, 2008), there are convergent results that indicate that social behaviour is particularly impaired in individuals with FASD (Olson et al., 1998; Schonfeld et al., 2006a; Thomas, Kelly, Mattson, & Riley, 1998). In fact, studies in humans and animals support the possibility that prenatal exposure to alcohol may have a direct effect on social functioning (Kelly & Dillingham, 1994; Thomas et al., 1998).

The majority of research examining adaptive behaviours has been conducted in children 14 years of age or younger. The lack of research in an adult population poses a problem as deficits in adaptive behaviour are life-long and may become more prominent with age (Olson et al., 1998; Streissguth et al., 1991). While difficulties relating to adaptive behaviour have been noted in young children with FASD (Jirikowic et al., 2008), it appears that social skills plateau at approximately age 6 (Streissguth et al., 1991). In one of the few studies examining adaptive functioning in adolescents and adults with FASD, Streissguth and colleagues (1991) administered the VABS to 61 participants with FAS or FAE and found greater impairments in the area of social skills and, comparatively, a lesser extent of impairments in daily living skills. Similarly, another study showed that adolescents between the ages of 14 and 16 years of age with FAS also had greater social impairments as measured by the Socialization scale of the VABS relative to the Communication and Daily Living Skills (Olson et al., 1998). Thus, as the individuals reach adolescence and adulthood, there is a larger discrepancy between their social skills and those of same-aged peers. Thomas and colleagues (1998) have hypothesized that this difference may be exacerbated by environmental demands, due to the fact that adolescents and adults face greater societal expectations to conform to acceptable social conduct. The Socialization scale of the VABS assesses behaviours such as “asks permission before using objects belonging to or being used by another” and “responds appropriately to reasonable changes in routine” (Sparrow et al., 2005). Whereas socially inappropriate behaviour such as violating boundaries and throwing a tantrum in response to an unexpected change in routine may be tolerated in childhood, such behaviour is considered to be developmentally inappropriate in adulthood (Thomas et al., 1998). The deficits in maladaptive behaviour become more apparent

with age and in adults the impairments may interfere with the individual's ability to form friendships and relationships, maintain employment, and live independently.

### **Limitations of the Neurobehavioural Model**

While the neurobehavioural model is in large part used to explain criminality in FASD, it has some important limitations. In particular, the model fails to take extrinsic factors into account, such as the social environment of the individual, parent or caregiver characteristics, substance use, and broader community influences (Lynch, Coles, Corley, & Falek, 2003). Given that secondary disabilities develop as a result of the interaction between primary disabilities and environmental influences, it is important to consider how the psychosocial milieu of the individual may contribute to criminal behaviour. Coggins, Timler, and Olswang (2007) suggest that there is a need for broader, systematic research in order to examine how adverse environmental factors can impact the developing nervous system. Furthermore, the neurobehavioural model may be misleading because it is based on observed deficits in FASD and their hypothesized effect on criminal conduct; thus, although it ascribes criminality to known deficits, it fails to take into account other risk factors, such as negative social influences and unemployment, that have been well-established in research conducted within the general correctional population.

### **The Risk-Need-Responsivity Model**

To address the shortcomings of previous models and the lack of empirical evidence to support these existing frameworks, the risk-need-responsivity (RNR) model was developed (Andrews & Bonta, 2006). Drawing on general theories of personality as well as social psychology, the RNR model is a parsimonious, empirically-derived model that aims to identify

the predictors of criminal conduct and understand their responsiveness to change through rehabilitative efforts (Andrews & Bonta, 2010). As such, the RNR model has been widely used to guide correctional assessment and treatment (Andrews, Bonta, & Wormith, 2011). There are three main tenets of the RNR model: risk (the level of risk of recidivism), need (the criminogenic needs that drive delinquent behaviour) and responsivity (delivering services in a way that is appropriate for the individual's characteristics, including strengths, vulnerabilities, learning style, and culture). In particular, the RNR model is centred on identifying the factors that predict recidivism in order to develop a treatment plan geared to the unique strengths and vulnerabilities of the individual (Andrews & Bonta, 2010).

### **Risk and Need Factors**

Criminogenic risks can be categorized as static or dynamic (Andrews & Bonta, 2010). Static risk factors are those that cannot be changed, such as criminal history, juvenile criminality, and family dynamics (Andrews & Bonta, 2010). Due to their fixed nature, static factors cannot be targeted to reduce the likelihood of recidivism. Dynamic risk factors, on the other hand, are situational and can be presumably ameliorated through intervention. Thus, unlike static risks, dynamic risk factors such as antisocial cognitions, antisocial associates, unemployment, and substance use can be targeted to reduce the likelihood of recidivism (Andrews & Bonta, 2006; Gendreau, 1996; Ogloff & Davis, 2004). While Andrews and Bonta (2010) differentiate between static risk factors ("risks") and dynamic risk factors ("needs"), both can be used to predict criminality.

Based on meta-analytic research on criminal conduct, the "central eight" risk/need factors were identified. Subsequently, these eight factors were divided into two categories denoting the

best established risk factors and moderate risk factors for criminal conduct (Andrews & Bonta, 2010). The strongest risk/need factors are a history of antisocial behaviour, antisocial personality patterns, antisocial associates, and antisocial traits such as antisocial cognitions. Moderate risk factors include family and marital circumstances, academic/occupational achievement, leisure and recreation, and substance abuse (Andrews & Bonta, 2010). Together, these factors may help elucidate some of the personal characteristics and environmental factors that drive criminal behaviour. Given the high prevalence of criminality in FASD, it is important to review each of the “central eight” risk factors might contribute to criminality.

**History of Antisocial Behaviour.** A cogent predictor of future delinquent behaviour is a history of past antisocial behaviour. For the purpose of studying offending behaviour, antisocial behaviours refer to actions that are inconsistent with societal norms and rules (Andrews & Bonta, 2010). Some of the hallmarks of criminality in FASD include being arrested at a young age. A comprehensive study on secondary disabilities found that the mean age at which individuals with FASD began to face trouble with the law was 12.8 years (Streissguth et al., 2004). Individuals with FASD often engage in multiple offenses, particularly during adolescence (Brown et al., 2012). Nevertheless, the offenses tend to be low-grade and do not, for the most part, escalate to stronger offenses. Interestingly, the offenses perpetrated by individuals with FASD tend to occur in the presence of peers and are rarely carried out alone (Brown et al., 2012).

Although past patterns of behaviour may be strong indicators of future behaviour, developmental considerations should be taken into account. For example, some antisocial tendencies can be present from childhood, with many children engaging in behaviours such as lying, cheating, stealing, and fighting (Brown et al., 2012). However, unlike their typically developing peers, these behaviours do not dissipate with age in individuals with FASD. It has

been postulated that the challenging behaviours may be a reflection of their deficits. For instance, impairments in language, emotional regulation, and understanding of social cues can impede these individuals from learning appropriate social behaviour. Additionally, difficulty with inhibition and impulsivity may result in difficulty inhibiting socially inappropriate behaviour (Schonfeld et al, 2006a).

Another indicator used to gauge antisocial behaviour is the presence of rule violations. Indeed, individuals with FASD have a strong tendency to violate their terms of probation (Brown et al., 2012). However, failure to comply with probation requirements has been attributed to their neuropsychological deficits, including difficulty keeping track of time, difficulty navigating complex transit systems to attend meetings and appointments, memory impairments that may lead them to forget about appointments, and difficulty inhibiting behaviour that is contraindicated in the agreement.

Indeed, it appears that individuals with FASD have a strong history of antisocial behaviours. However, if these behaviours are being maintained by neuropsychological deficits, it calls into question whether traditional rehabilitation supports will benefit. Furthermore, the bulk of research on FASD and criminality has revealed some strong patterns that are static and therefore cannot be altered by traditional rehabilitative efforts. Not surprisingly, there is strong support from researchers and professionals alike to intervene at the behavioural level to increase noncriminal behaviours and decrease criminality (Andrews & Bonta, 2010).

**Antisocial Personality Patterns.** In the context of criminogenic risks, personality is defined as the patterns of thinking, feeling, and acting that govern an individual's responses in different circumstances. There are several traits associated with an "antisocial" personality

pattern, including impulsivity, high sensation seeking, aggression, and a disdain for others that is characterized as callous (Andrews & Bonta, 2010). Despite paucity in research on personality characteristics of individuals with FASD, extant literature suggests that impulsivity, aggression, and lack of empathy for others are all inherent traits of the diagnosis (Brown et al., 2012). It has been well-established that individuals with FASD are impulsive as a result of executive dysfunction. Not surprisingly, these individuals tend to engage in impulsive and opportunistic criminal behaviour rather than sophisticated, premeditated acts (Brown et al., 2012). As an example, the types of crimes perpetrated by individuals with FASD include assault in response to a perceived threat or shoplifting small items that are readily available but offer little gain (Brown, Wartnik, Connor, & Adler, 2010).

Undeniably, aggression plays an important role in criminality for individuals with FASD. Crimes against a person account for 45% of law violations (Streissguth et al., 2004). Unlike instrumental aggression that can occur with the purpose of obtaining a reward, the aggression seen in FASD is more reactive than proactive. It is a response to a perceived provocation or threat and is normally associated with feelings of anger or fear (Brown et al., 2012). Accordingly, the purpose of reactive aggression is to respond (albeit in a maladaptive way) to a distressing and frustrating situation. As Brown and colleagues (2012) explain, “reactive aggression is synonymous with ‘defensive,’ ‘angry,’ ‘hot-blooded,’ ‘impulsive,’ ‘emotional,’ and ‘retaliatory’ aggression” (Brown et al., 2012, p. 772). Once again, it appears that deficits in emotional regulation and impulsivity are at the heart of the delinquent behaviour associated with FASD.

**Antisocial Associates.** As previously mentioned, individuals with FASD have marked impairments in social skills (Schonfeld et al., 2006a). Interestingly, despite their apparent easy

social bonding and desire to please others, individuals with FASD seem unable to grasp social cues, resulting in difficulties with social interactions (Streissguth & Giunta, 1988). In fact, the lack of positive relationships with their peers can often result in bullying, ostracism, and disruptive behaviour, which in turn exacerbate their social difficulties (Kully-Martens, Denys, Treit, Tamana & Rasmussen, 2012). Furthermore, social impairments can contribute to the development of secondary disabilities, particularly criminal behaviour (Fast & Conry, 2009; Kelly, Day, & Streissguth, 2000; Schonfeld et al., 2006a).

Although the relationship between poor social skills and criminality has been established in the general population (Kupersmidt, Coie, & Dodge, 1990), this relationship has not been studied systematically in individuals with FASD. Nevertheless, Fast and Conry (2009) propose that without the appropriate social skills, individuals with FASD may be vulnerable to being negatively influenced by their peers. Specifically, deficits in social skills may increase the likelihood that individuals with FASD will be rejected by their well-adjusted peers, which in turn makes it more likely that they will associate with peers who show greater maladaptive behaviours (Schonfeld et al., 2006a). Their vulnerability to negative peer influences is particularly problematic if they associate with individuals involved with criminal activity as their impulsivity, desire to please others, and difficulty understanding consequences make them susceptible to criminality and victimization (Fast & Conry, 2009; Thomas et al., 1998). Their vulnerability to negative peer influences is further compounded by the lack of supervision resulting from being placed in multiple foster homes, group homes, or youth corrections services which increase their contact with delinquent peers (Lynch et al., 2003; Paley & Auerbach, 2010).

**Antisocial Cognitions.** Antisocial cognitions refer to the attitudes, values, and beliefs an individual holds that are in favour of criminality (Andrews & Bonta, 2010). Indeed, there is an

assumption in the justice system that criminals engaging in antisocial behaviours have an understanding of social conventions yet choose to violate the rules nonetheless. However, the deliberate action of such rule violation is predicated on two abilities: the ability to understand that one's behaviour is going against social norms and the ability to inhibit the behaviour. Yet these abilities seem to be notable vulnerabilities for individuals with FASD, suggesting that they are more likely related to an inability to inhibit inappropriate behaviour, predict consequences, and understand the implications of their actions rather than a blatant disregard for prosocial thinking (Moore & Green, 2004). In fact, many professionals in the criminal justice system have gone as far as calling into question whether offenders with FASD have the *mens rea* or "guilty mind" to be classified among general offenders, which implies that the individual understands that his or her actions are against the law and therefore engaged in the act with criminal intent (Brown et al., 2010; Fast & Conry, 2009; Moore & Green, 2010; Roach & Bailey, 2009).

To highlight the importance of the issue of criminal responsibility, a panel of experts on FASD reviewed over 40 cases from 2007 to 2010, almost half of which involved capital murder. They found that almost all of the offenders in question had significant deficits in EF, which likely contributed to their behaviour in an unstructured environment matched with distressing circumstances (Brown et al., 2010). However, the Canadian justice system operates on the assumption that the ability to understand right from wrong is determined by IQ; consequently, neuropsychological deficits are not taken into consideration and individuals with an IQ over 70 are considered to be fit to stand trial despite their numerous impairments (Roach & Bailey, 2009). There is a marked need for specialized forensic assessment to determine whether or not an individual with FASD has the ability to understand their rights in the adjudicative process (McLachlan, Roesh, Viljoen, & Douglas, 2013). Thus, more research is needed to understand the

role of cognition in criminality in offenders with FASD and to determine if criminal behaviour is linked to cognitive deficits, antisocial cognitions, or both.

**Moderate risk factors.** Although less predictive of recidivism than the strong risk/need factors, it is important to consider the role of familial circumstances, academic and occupational achievement, leisure and recreation, and substance abuse in criminal conduct (Andrews & Bonta, 2010). It is estimated that 53% of individuals with FASD have a history of truancy, regardless of their gender (Ladue et al., 1992). Moreover, Streissguth and colleagues (1997) found that disrupted school experiences led to a twofold increase in the likelihood of criminality, which may be due to the fact that they have more unsupervised time when they are not attending school. Furthermore, because many individuals reside in multiple households throughout their life, it is also possible that there is a lack of parental supervision to re-direct individuals with FASD from maladaptive behaviour (including substance use) to more constructive leisure activities (Paley & Auerbach, 2010). Similarly, research has found that 79% of adults with FASD aged 21 years or older have difficulty maintaining employment (Streissguth et al., 1997). A longitudinal study on adults with FASD found that even when employment preparatory programs were provided, many individuals with FASD were unemployed and unable to live independently (Spohr, Willms, & Steinhausen, 2007). As a result, many individuals require lifelong support from family members. Given the importance of familial support for adults with FASD, the role of the home environment on criminality will be discussed later on.

## **Responsivity**

In examining the risk and need factors that may contribute to criminality in individuals with FASD, it becomes apparent that the interaction between existing neurobehavioural deficits

and adverse, environmental outcomes lead to the probable development of secondary disabilities. Thus, traditional treatments employed in correctional institutions may not be appropriate for individuals with FASD, as stipulated by the responsivity component of the RNR model. For instance, programs with a cognitive emphasis that offer few opportunities for repetition are not likely to be effective for individuals with FASD (Boland, Chudley, & Grant, 2002; Brown et al., 2012). Similarly, given the permanent nature of primary disabilities, it is likely impractical to employ a deficit model aimed at improving impairments such as cause-and-effect thinking (Malbin et al., 2010). Instead, interventions should be aimed at reducing the impact of environmental risks while augmenting protective factors (Olson et al., 2009).

Traditionally, research has focused on identifying risk factors that increase the likelihood of criminal behaviour, but less emphasis has been placed on the protective factors that may result in more positive life outcomes (Salekin, Lee, Dillard, & Kubak, 2010). Previous research has shown that there are protective factors that prevent or mitigate the effects of secondary disabilities for individuals with FASD. For example, living with a caregiver, not being vulnerable to manipulation, and requiring minimal levels of support, all reduce the likelihood of secondary disabilities in FASD (Streissguth et al., 1997). However, the eight most important protective factors identified were living in a nurturing, positive home environment for at least 72% of life; receiving a diagnosis of FASD before the age of six; never experiencing violence; remaining in each living situation for at least 2.8 years; living in a good quality home between the ages of 8 and 12; receiving developmental disability services; receiving a diagnosis of FAS; and having basic needs met for a minimum of 13% of life. The role of these protective factors in the mitigating secondary disabilities demonstrates the importance of studying the familial context of individuals with FASD (Streissguth et al., 2004).

## **Family Experience**

In considering the impact of environmental risk and protective factors on the individual and the family, it has been suggested that interventions should target both individuals and their caregivers (Olson, Oti, Gelo, & Beck, 2009; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Given that the protective factors delineated by Streissguth and colleagues (2004) are intricately linked with the family system, interventions should not only target the individual, but also the family members (Olson et al., 2009; Rasmussen et al., 2008). However, there is little research describing the experience of caregivers and family members in dealing with their child's secondary disabilities, particularly with respect to criminality.

The home environment has a strong impact on the outcome for individuals with FASD, yet relatively little is known about families of children with FASD (Olson, Rudo-Stern, & Gendler, 2011; Watson, Coons, & Hayes, 2013a). In a study examining the socio-emotional development of foster children with FASD, it was found that experiencing trauma and having disabilities or illnesses that resulted in impaired functioning were associated with greater socio-emotional problems, more severe neurocognitive impairments, and increased rates of behavioural problems (Koponen, Kalland, Autti-Rämö, 2009). However, entering foster care at a young age helped mitigate the adverse effects of being placed outside of the biological family. The authors concluded that the caregiving environment had an effect on both primary and secondary disabilities and is therefore an important variable to consider in future research (Koponen et al., 2009).

While the majority of research has focused on identifying the challenging behaviours associated with prenatal alcohol exposure, further research is needed to understand how the

behavioural problems impact parenting stress in families of children with FASD (Paley, O'Connor, Kogan, & Findlay, 2005). Research has found that parents of school-aged children with FASD experience elevated levels of parenting stress (Jirikowic, Olson, & Astley, 2012; Paley, O'Connor, Frankel, & Marquardt, 2006; Paley et al., 2005; Watson et al., 2013a). Paley and colleagues (2005) found that biological mothers of children with FASD reported high parenting stress on the Parenting Stress Index (PSI; Abidin, 1995), a validated self-report measure of parenting stress. Employing path analysis, the authors concluded that maternal stress was related to a high degree of externalizing behaviours (e.g., aggressive, oppositional, or defiant behaviour) as well as fewer parental supports (Paley et al., 2005). Similarly, impairments in EF and adaptive functioning, coupled with greater externalizing behaviours and internalizing behaviours (e.g., anxious or depressed behaviour), were collectively found to contribute to elevated levels of parenting stress on the PSI in a sample of biological and adoptive parents (Paley et al., 2006). Thus, while biological families may face increased stressors related to substance use, high levels of parenting stress are reported by all family types. Given that only 20% of individuals with FASD live with their biological mothers (Astley, Bailey, Talbot, & Clarren, 2000; Streissguth et al., 2004), it is important that research include birth, adoptive, and foster parents to be representative of the family experience.

Jirikowic and colleagues (2012) investigated the impact of various child neurobehavioural characteristics, including EF, sensory processing, challenging behaviours, adaptive behaviour, and cognitive functioning on caregiving stress. The authors found that parenting stress was predicted by sensory processing difficulties and problems with behavioural regulation, an important component of EF. Furthermore, impairments in inhibitory control, cognitive flexibility, and emotional regulation were correlated with high levels of parenting

stress. The findings from the study suggest that neurobehavioural impairments resulting from prenatal alcohol exposure contribute to the experience of parenting stress in birth, adoptive, and foster families and may be an underlying factor to the development of challenging behaviours exhibited by children with FASD (Jirikowic et al., 2012). As such, it is possible that the experience of parenting stress in FASD is different than that of parents raising children with other developmental disabilities (Olson et al., 2007).

A recent mixed methods study compared the experience of parenting stress in families of children with FASD or autism spectrum disorder (ASD; Watson et al., 2013a; Watson, Hayes, Coons, & Radford-Paz, 2013b). Although both sets of parents reported elevated levels of parenting stress on the Parenting Stress Index - Short Form (PSI-SF; Abidin, 1995), parents of children with FASD experienced greater overall parenting stress than parents of children with ASD (Watson et al., 2013a). To gain a better understanding of the specific demands and stressors faced by parents of children with FASD or ASD, qualitative interviews were conducted. Similar stressors were identified by both groups, including challenges associated with the diagnostic process, difficulty managing problematic behaviour, lack of supports for families, and the need for parents to undertake multiple roles such as educator, case manager, and advocate. Nevertheless, differences emerged between the groups. In particular, parents of children with FASD expressed concern about criminal behaviour (Watson et al., 2013b), which is consistent with extant research that individuals with FASD are overrepresented in the criminal justice system (Streissguth et al., 2004; Fast et al., 1999).

To date, few studies have examined the experience of families of children with FASD and the legal system. In an analysis of secondary data derived from testimonials provided by parents of children with FASD, Caley, Winkelman, and Mariano (2009) identified caregivers'

concern with keeping their children safe as a recurrent theme spoken by parents. As one parent stated, “Soon all of his [my son’s] friends were from troubled homes and they would use my son and he would get caught and they went free. He was doing anything to be liked and to have friends.” (Caley et al., 2009, p. 185).

Although fear of harm may be a common concern for parents of children with a developmental disability (Ivey, 2004; Tymchuk, Groen, & Dolyniuk, 2000), concerns of criminality and subsequent incarceration appears to be a predominant fear for parents of children with FASD (Watson et al., in press). The authors conducted a mixed methods study comparing the expectations for the future and the level of hope reported by parents of children with autism or FASD. While both parents of children with ASD and FASD expressed concern for their child’s safety, parents of children with FASD expressed particular worry about their child’s likelihood of facing trouble with the law. In fact, when asked about his child’s future, one birth father responded, “I see Pierre [my son] sitting in a jail cell.” (Watson et al., in press, p. 19). Along the same vein, one mother responded simply, “Jail.” (Watson et al., in press, p. 18). Thus, for many parents of children with FASD, trouble with the law appears to be an unfortunate yet inevitable outcome.

In addition to worrying about their child’s involvement with the law, parents expressed concern regarding the lack of understanding of FASD by professionals in the criminal justice system. Salmon (2008) conducted a qualitative study examining the experience of eight birth mothers to children with FASD. Among the themes that emerged from the interviews, Salmon (2008) found that birth mothers reported being seen as a causal factor in their child’s criminality. The birth mothers also reported lack of understanding on the part of police officers, which ultimately led to them feeling blamed for their child’s behaviour (Salmon, 2008).

Among the studies conducted on families of children with FASD, the majority have focused on the negative impact of raising a child with a disability (Watson, Hayes, & Radford-Paz, 2011; Olson et al., 2009). However, few studies have examined the protective factors that contribute to positive life outcomes. According to families, factors such as access to educational and support programs (Brown & Bednar, 2004; Phung, Wallace, Alexander, & Phung, 2011), support from other families of children with FASD (Salmon, 2008), structure and routine (Gardner, 2000), being proactive by anticipating and preventing challenges, and self-care strategies for parents (Brown & Bednar, 2004) are important factors that contribute to the well-being of families. Despite the lifelong impairments associated with FASD, the bulk of research has focused on the experience of families with school-aged children; consequently, little is known about the experience of families of adults prenatally exposed to alcohol. From the perspective of intervention and prevention, it is important to consider caregivers' experiences in order to minimize the barriers they face and increase supports where needed.

### **Purpose**

Despite being identified as a significant social problem, there is a paucity of research on the criminal behaviour of individuals with FASD (Chudley et al., 2005; Streissguth et al., 2004). It is believed that delinquent behaviour is the result of the interaction between primary disabilities (e.g., deficits in EF) and adverse life outcomes (e.g., unstable or unsafe home environment), which in turn lead to the development of secondary disabilities. However, the effects of secondary disabilities can be mitigated or prevented through protective factors. Most studies have focused on universal protective factors that apply to all secondary disabilities, yet little research has looked at which protective factors target specific secondary disabilities

(Streissguth et al., 1997). Thus, it is important to look at the protective factors that may specifically prevent individuals with FASD from experiencing legal problems.

The aim of this exploratory study was to investigate the potential factors that contribute positively and negatively to the experience of legal problems in adults with FASD. The guiding research questions for this thesis were;

- 1) What are the challenges in conducting research on adults with FASD?
- 2) What are the cognitive and environmental factors that are associated with criminal behaviour in adults with FASD?
- 3) Based on their experience raising a child with FASD, which risk factors do caregivers believe contributed to their child's legal problems?
- 4) According to caregivers, what are the protective factors that prevent individuals with FASD from experiencing trouble with the law?

The results of this study will identify particular cognitive and environmental factors that protect individuals with FASD from criminality, in turn informing preventative and rehabilitative programs for offenders with FASD. In order to capture the complexity of the interaction between primary disabilities and the caregiving environment, a mixed methods approach will be employed. The themes from the qualitative component and the statistical data analysis will be integrated to determine if the findings from each approach are convergent or divergent (Merriam, 2002; Teddlie & Tashakkori, 2009).

### **Reflexivity**

In qualitative studies, the researcher is the primary instrument through which data is collected and analyzed. Investigators carry their own biases, assumptions, and worldviews that

may add an element of subjectivity to the research process. In order to increase the credibility of studies, it is important for the researcher to reflect on how their personal perspectives may influence the outcome of the study (Merriam, 2002). In the following section, I will identify some of my personal and professional experiences that may have influenced data collection, analysis, and interpretation.

My interest in developmental disabilities began in adolescence and has since guided my academic and professional experiences. My decision to pursue post-secondary studies in the field of psychology was highly influenced by my desire to learn more about human development. Upon completing an undergraduate degree in psychology I became a research assistant to my current supervisor, Dr. Shelley Watson. Through her study titled “Family Experience of Raising a Child with Developmental Disabilities in Northern Ontario”, I was introduced to family research and FASD. The experience of conducting research with families gave me a strong appreciation of the challenges and adversities faced by parents of children with developmental disabilities. More importantly, however, my involvement in the research project also allowed me to see the strength and resilience of families. In fact, it was the persistence and dedication of parents that inspired this research project. Although every single family spoke of the legal issues experienced by their children, parents were hopeful that their experiences might have a positive impact on a family facing similar challenges. I recognize that hearing these statements had a significant influence on my decision to study the experience of families with FASD for my Master’s thesis.

In addition to my involvement in the broader family research project, I have worked with families in clinical settings. I completed a practicum in an outpatient eating disorder program where I had the opportunity once again to work with families. The program employed a family-

centred treatment model that emphasized the need to support family members as well as the identified client. It is important to note that while family treatment is strongly advocated for children and adolescents, families were also included with adult clients. This experience reaffirmed my belief that families play an integral role in their child's well-being, regardless of age. Therefore, I acknowledge that I conducted this research project with the conviction that targeting the family system is an essential component of treatment.

A recurrent theme that emerged from the interviews was the lack of social and financial support for families of children with FASD in comparison to other disabilities, such as autism. These statements provoked a strong feeling of injustice in me and as such, I found myself occasionally allying with parents against the social system. As in recognizing this bias, I made a persistent effort to separate my personal views from my role as the researcher.

It is also possible that personal characteristics such as socio-economic status can also play a role in researcher bias. In the event that the researcher's personal characteristics do not match those of the participants', there is a risk of misinterpretation or misrepresentation of data. In my upbringing, I was fortunate to have had access to any services necessary, including extended health benefits. However, this is not the reality for many families. Given that some of the questions included in the semi-structured interview related to the home environment, having basic needs met, and having access to diagnostic and treatment services, an ongoing effort was made to understand the experience of participants while recognizing any assumptions that may arise from my own personal experience. In recognizing this potential bias, I was careful to ask families about some of the additional barriers and challenges that be influenced by socio-economic status, including those relating to health, housing, finances, and supports.

It is through the lens of positive psychology and the humanistic approach that I designed the present study, which seeks to go beyond identifying risk factors by answering the question “What protects individuals with FASD from criminality?” An effort was made to use open-ended questions in the semi-structured interview (see Appendix A for the interview guide); however, my worldview may have influenced the avenues that I followed during the interviews in an attempt to understand the strengths and self-actualizing potential of individuals with FASD and their family members. During the interviews, I occasionally found myself focusing more on the strengths of the individual and their family members and less on their vulnerabilities. Although I found that the families in this study demonstrated great resilience in the face of adversity, I was also surprised to find that the majority of families felt helpless and hopeless when it came to protecting their adult children from legal issues. Given that this study was an exploratory inquiry on the factors associated with criminality in FASD, I monitored my responses and follow-up questions to ensure that participants had equal opportunity to discuss both their strengths and limitations.

Running Head: Methodological Challenges

**Methodological Challenges in Conducting Research with Adults who have FASD**

Elisa Radford-Paz

Laurentian University

### **Abstract**

Although Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability, there is a paucity of research on the longitudinal effects of prenatal alcohol exposure. In part, the lack of systematic studies has been attributed to the methodological challenges that hinder research. In the current paper, the author outlines the challenges encountered in conducting a mixed methods study that sought to compare the experience of offenders and non-offenders who have FASD.

Methodological issues such as having a small sample size, the use of convenience sampling, the inclusion of adults without a formal diagnosis, and difficulty in establishing operational definitions limited the ability to draw overarching conclusions and compare the findings to previous research. Furthermore, special considerations were taken in the selection and administration of psychometric measures, which may not be suitable to the unique needs and vulnerabilities of individuals with FASD. In addition, practical limitations interfered with the research process, including recruitment issues and high attrition rates related to the many adverse life outcomes experienced by individuals with FASD. Recommendations to guide future research are also discussed.

### **Methodological Challenges in Conducting Research with Adults who have FASD**

Despite growing concern with the economic and social implications associated with FASD (Amendah, Grosse, & Bertrand, 2011; Chudley et al., 2005; Nash et al., 2006; Popova, Lange, Burd, & Rehm, 2012; Stade, Ungar, Stevens, Beyen, & Koren, 2007), the lifelong teratogenic effects of prenatal alcohol exposure remain understudied (Streissguth & O'Malley, 2000). Furthermore, the extant research on FASD is often hindered by a myriad of conceptual, methodological, and practical limitations (Cronk & Weiss, 2007; Irner, 2012; Warren, Hewitt, & Thomas, 2011). Several methodological issues have been identified by researchers, including the paucity of research using large sample sizes (e.g., Ase et al., 2012; Carr, Agnihotri, & Keightley, 2010; Chasnoff, Wells, Telford, Schmidt, & Messer, 2010), the need for more consistency in sample characteristics and operational definitions across studies (e.g., Arenson et al., 2010; Pei, Job, Kully-Martens, & Rasmussen, 2011), as well as concerns with the limitations of the psychometric measures employed (e.g., Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012a; Schonfeld, Paley, Frankel, & O'Connor, 2006). Contributing to the challenge of addressing the methodological limitations are practical barriers relating to the recruitment and retention of participants, particularly when studying adults with FASD (May et al., 2009; Sayal, 2007).

The aim of this paper is to identify some the methodological challenges related to the design and implementation of research with adults prenatally exposed to alcohol and to propose solutions to guide future research. This paper draws on the author's experience conducting a mixed methods study on the protective factors associated with criminality in adults with prenatal alcohol exposure to reflect on some important limitations that may be encountered when conducting similar research.

### **Fetal Alcohol Spectrum Disorder**

FASD is an umbrella term that refers to the continuum of physical, neurobiological, and behavioural consequences resulting from gestational exposure to ethanol. Although FASD is not a diagnostic label, diagnoses of fetal alcohol syndrome (FAS), partial FAS (pFAS), and alcohol-related neurodevelopmental disorder (ARND) are used to describe the specific congenital birth defects resulting from prenatal alcohol exposure (Astley & Clarren, 2000). According to Canadian diagnostic criteria, the teratogenic effects of alcohol are characterized by facial dysmorphism, growth deficiency, and abnormalities of the central nervous system (Astley & Clarren, 2000). In particular, specific craniofacial malformations have been associated with prenatal alcohol exposure, including short palpebral fissures, flat upper lip, flattened philtrum, and a flat midface (Connor & Streissguth, 1996). Furthermore, individuals who were prenatally exposed to alcohol may have growth deficits such as low birth weight, decelerating weight that is not attributable to malnutrition, and a disproportionate weight-to-height ratio (Chudley et al., 2005). Exposure to alcohol during pregnancy can also lead to neurodevelopmental abnormalities of the central nervous system, such as microcephaly, agenesis of the corpus callosum, and impaired functioning of the frontal lobe, basal ganglia, and hippocampus (Guerri, Bazinet, & Riley, 2009).

In addition to the structural abnormalities resulting from prenatal alcohol exposure, individuals with FASD experience a host of cognitive and behavioural problems (Streissguth, Barr, Kogan, & Bookstein, 1997). These permanent deficits, called “primary disabilities”, are present from birth and include impairments in motor coordination (e.g., Connor & Streissguth, 1996), executive functions (e.g., attention, working memory, inhibitory control, planning; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008), academic achievement (Godel et al.,

2000), and adaptive behaviour (e.g., Schonfeld et al., 2006). Furthermore, FASD is the leading preventable cause of intellectual disability in North America (O’Leary et al., 2012). Primary disabilities, when combined with biological vulnerabilities and adverse environmental factors, can give rise to “secondary disabilities” (Streissguth et al., 1997; Streissguth et al., 2004).

Secondary disabilities include comorbid mental health problems, suspension, expulsion or dropping out of school, legal problems, inappropriate sexual behaviour, confinement as a result of incarceration or due to the necessity of inpatient treatment, and problems with dependent living (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Streissguth et al., 2004). Unlike primary disabilities, however, secondary disabilities can be mitigated through interventions or protective factors such as having a stable and nurturing home environment, receiving an early diagnosis, and receiving supports and services for developmental disabilities (Streissguth et al., 1997)

The prevalence of FASD in Canada is 9.1 in 1000 live births (Health Canada, 2006), while the prevalence of FASD in the United States is at least 2 to 7 in 1000 live births (May et al., 2009). However, many researchers argue that these estimates are artificially low as they fail to take limitations into account, including the methodology employed in research studies, the lack of systematic studies using routine screening clinics, the discrepancies between existing diagnostic classification systems, and the challenge of identifying the effects of prenatal alcohol exposure in the absence of facial dysmorphology (Eriksson, 2007; Clarren & Lutke, 2008; May et al., 2009). To address common limitations found in previous literature, a review of prevalence studies based on screening and diagnosis of younger school children was undertaken (May et al., 2009). May and colleagues (2009) estimate that the prevalence rate of FASD in the United States and Western Europe is likely 2-5%, making it an important yet understudied issue that has a

substantial impact on health care, educational, and judicial sectors. In fact, the annual economic impact of FASD in Canada is estimated to be at least \$344 million (Stade et al., 2007).

### **Benefits and Challenges of Research on FASD**

Research has served as the impetus for the advancements, both scientifically and clinically, in the understanding of FASD. Since the first published accounts of the clinical effects resulting from prenatal alcohol exposure (Jones & Smith, 1973; Lemoine, Harousseau, Borteryu, & Menuet, 1968), research has sought to delineate more consistent diagnostic criteria (Clarke & Gibbard, 2003). Early research on FASD employed the diagnostic terms FAS and Fetal Alcohol Effects (FAE) to refer to the constellation of effects caused by prenatal alcohol exposure (Streissguth et al., 1991). The term FAS, coined by Jones and Smith (1973), refers to individuals who meet the three diagnostic criteria: facial dysmorphology, growth deficiency, and damage or dysfunction of the central nervous system. FAE, on the other hand, refers to individuals who were exposed to alcohol prenatally and have subsequent dysfunction of the central nervous system, yet do not have any of the physical characteristics (Rosett, 1980). As research on the multifarious nature of FASD emerged, it became apparent that the diagnostic categories needed to be redefined to include pFAS, ARND, and alcohol-related birth defects (ARBD) to more accurately reflect the possible teratogenic effects of alcohol (Chudley et al., 2005). Indeed, a number of reviews have indicated that standardization in diagnostic criteria have increased the consistency and reliability of diagnoses for disabilities related to gestational alcohol exposure (Astley et al., 2009; Hoyme et al., 2005; Manning & Hoyme, 2007; Mattson et al., 2010a).

Likewise, research has played a critical role in the development of evidence-based approaches to treatment and prevention (Salmon & Clarren, 2010). Furthermore, research has

served as the conduit that translates scientific knowledge into policies and recommendations that are more sensitive to social and cultural influences (Badry & Felske, 2010). More recently, researchers have begun collaborating on large-scale, multinational studies of FASD that employ a standardized methodology in order to control for ethnic, cultural, and social variables (Mattson et al., 2010a; Mattson et al., 2010b; Peadon, Fremantle, Bower, & Elliott, 2008). In spite of the significant contributions of research to the conceptualization of FASD, some substantial methodological challenges continue to influence the understanding of the lifelong teratogenic effects of prenatal alcohol exposure.

While there is overwhelming evidence indicating that FASD is an important social issue, there is consensus among professionals that more research is needed to further understand the effects of prenatal alcohol exposure (Nixon, Prather, & Gilbertson, 2010). In part, the dearth of knowledge on FASD is attributed to some of the methodological issues associated with research on this topic. In particular, researchers have cited three important methodological limitations: challenges relating to sample size (Pei et al., 2011), lack of consistency in the nomenclature employed and the corresponding operational definitions (Arenson et al., 2010), and the appropriateness of measures utilized (Kully-Martens et al., 2012a). The limitations of past and current research have been well-established, yet there is a lack of guidelines to create more meaningful and sustainable research. In this article, the challenges associated with conducting mixed methods research with individuals with FASD are identified.

### **Overview of the Research Project**

The purpose of the research project was to explore the cognitive and environmental factors that protect adults with FASD from criminality. A mixed methods approach was

employed, consisting of a battery of standardized psychological tests that were complemented by semi-structured interviews. This study was approved by the Laurentian University Ethics Board, in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants.

Adults with prenatal alcohol exposure and at least one caregiver or family member for each participant were invited to participate in this study. In order to compare the lived experience of offenders and non-offenders, both individuals with and without a history of trouble with the law were recruited for the study. Participants were recruited from community agencies in Ontario, Canada that provide support for individuals with FASD and their families, as well as support groups from across the province. Thirty-three support groups were contacted in total. Of the 17 families that expressed interest in participating in the study, eight families took part in the research project. Parents and caregivers represented a multitude of family types, including one biological mother, five adoptive parents, and two custodial grandparents. Pseudonyms are used throughout this paper to ensure participant confidentiality.

### **Methodological Challenges of Research on FASD**

In line with the limitations outlined in previous research, several practical and methodological challenges were encountered in conducting a study on criminal behaviour among adults with FASD. In part, the lack of larger sample sizes may be related to the fact that this population is hard to reach. Studies have shown that FASD is more prevalent in rural communities that are typically isolated (Bohjanen, Humphrey, & Ryan, 2009; May et al., 2009), thereby rendering it very difficult to recruit participants in these regions. Furthermore, the primary and secondary disabilities experienced by adults with prenatal alcohol exposure may

interfere with the research process by contributing to high attrition rates as well as limiting the psychometric measures that can be clinically appropriate for adults with FASD. Collectively, the challenges encountered in conducting research with adults who have FASD suggest that the unique characteristics of this population must be taken into account when designing and implementing scientific studies.

### **Sample Size and Sample Characteristics**

Extant research on FASD has been plagued with small sample sizes that do not allow for statistical analyses that detect small effects (Carr et al., 2010; Chasnoff et al., 2010; D'Onofrio et al., 2007; Fagerlund et al., 2012; Jirikowic, Kartin, & Olson, 2008a; Rasmussen, 2005; Sarkola, Kahila, Gissler, & Halmesmäki, 2007). In the present study, the small sample size was partly attributed to the challenges relating to the recruitment of participants. Although this research project relied on clinical samples to obtain a larger sample size, some of the characteristics of the participants such as the severity of impairments do not allow the research findings to be generalized to a broader population (Kully-Martens et al., 2012a; Vaurio, Riley, & Mattson, 2011). It is therefore important to consider the sample size and characteristics of the sample when interpreting findings.

**Small sample size.** One of the primary challenges encountered when conducting this study was the recruitment of participants. A respondent-driven sampling technique, whereby participants were recruited by word of mouth from support groups and community agencies, was employed. This technique, sometimes called snowball sampling, is often used with hard to reach populations to address the challenge of relying on random sampling (Benoit, Jansson, Millar, & Phillips, 2005). Several attempts were made to contact potential participants, including sending

information about the study via e-mail to online parent support groups, as well as attending parent support meetings and FASD conferences in person to hand out flyers with information about the study. All participants were recruited from online parent support groups. Despite the author's efforts to attend meetings in person to invite families to take part in the study, not a single participant was recruited through face-to-face encounters. Furthermore, only two individuals with FASD participated in the quantitative portion of the study. As a result, the quantitative component was excluded in the final analysis of the results and only the qualitative findings were considered.

Although attempts were made to contact a multitude of support groups, there are few community-based agencies from which to recruit in Northern Ontario, making this population hard to reach unless they are connected to the services available to adults with FASD. Contributing to the challenge of recruiting participants is the lack of formal supports being offered specifically for FASD (Whitehurst, 2012), as well as the specific eligibility criteria for the few clinical supports available, such as having an IQ below 70 and deficits in adaptive abilities (Chudley, Kilgour, Cranston, & Edwards, 2007; Rutman & Van Bibber, 2010). In accordance with the methodological challenges identified in the literature, it is possible that the participants recruited through parent support groups may result in having a biased sample because participants accessing these services often represent severe cases that warranted such treatment in the first place (Chasnoff et al., 2010; Kully-Martens et al., 2012a; Pei et al., 2011; Vaurio et al., 2011). Consequently, clinical samples like the one employed in this study are likely to have a higher proportion of individuals with significant impairments in executive functioning, behavioural difficulties, and secondary disabilities than may be found in the general population

of individuals with FASD (Astley, 2010; McLennan, 2010). Thus, the results from this study may not be an accurate representation of all families of children with FASD.

**Terminology.** In addition to the challenges pertaining to recruitment and sample size, it was difficult to differentiate offenders from non-offenders in the present study. It is important to note that all eight of the families that participated in the study reported that their child had displayed delinquent behaviour at some point in their life. Some adults with prenatal alcohol exposure had engaged in criminal activity such as shoplifting; however, there was no police involvement. Because no criminal charges were laid, shoplifting may not have been formally described as trouble with the law according to the operational definitions commonly used in research. More specifically, some studies define offenders as individuals having involvement with the criminal justice system, such as problems with the authorities or charges or convictions of a crime (Clark et al., 2004; Fast, Conry, & Looock, 1999; Lynch, Coles, Corley, & Falek, 2003), while others rely on samples of individuals who have been incarcerated (Burd, Selfridge, Klug, & Juelson, 2003). Conversely, some studies do not label participants as offenders or non-offenders yet still measure delinquent behaviour such as stealing (Nash et al., 2006; Schonfeld, Mattson, & Riley, 2005); however, these behaviours are typically clustered with conduct problems such as fighting, which although maladaptive are not always considered to be criminal.

Nevertheless, there may be a qualitative difference between non-offenders who do not engage in any behaviour that is subsumed under the category of criminal activity and non-offenders who are involved in delinquent acts but have not had any involvement with police officers. The present study defined non-offenders as individuals who have never engaged in illegal activity such as shoplifting, fraud, assault, and destruction of property. However, using this definition, all adults with prenatal alcohol exposure in this study were considered to be

offenders. Although this speaks to the severity of the problem, it poses a methodological challenge as it does not allow for a clean comparison of offenders and non-offenders.

### **Researching adults with FASD**

Despite being a lifelong disability, there is a paucity of research on adults with FASD (Chudley et al., 2007; Connor, Sampson, Streissguth, Bookstein, & Barr, 2006). The lack of research may be due, in part, to the fact that individuals have only been diagnosed with FAS in the past 40 years (Jones & Smith, 1973), thus limiting the longitudinal data available for this population. Bearing in mind the historical challenges in providing a diagnosis relating to FASD, it is likely that many adults would not have received a formal diagnosis and would therefore be excluded from research. In line with existing research, this study included probable cases of FASD in the sample because many adults do not have a formal diagnosis (Chudley et al., 2007). Another challenge identified in the present study was the high rate of participant attrition related to the secondary disabilities associated with prenatal alcohol exposure. Together, the problems with the recruitment and retention of adults with FASD presented significant methodological barriers.

**Formal diagnosis.** In an attempt to increase the sample size in the present study, individuals strongly suspected of having FASD were included in the research project even in the absence of a diagnosis. Of the 10 children from eight families that participated in the study, only six individuals had received a formal diagnosis. Four individuals received a diagnosis in childhood, while the other two participants were diagnosed as adults. All four of the children who received an early diagnosis had the characteristic facial features, confirmed maternal alcohol consumption during pregnancy, or both. Audrey, an adoptive mother to a daughter with

FAS, indicated that the absence of physical characteristics posed a barrier to obtaining a diagnosis:

Unfortunately, my daughter's birth mother didn't drink on the 19<sup>th</sup>, 20<sup>th</sup>, 21<sup>st</sup> days of the pregnancy so she does not have the facial features. She looks perfectly normal...and we just tossed it aside and said that's not what she has. She doesn't look like that.

Four parents spoke of the multiple diagnoses their children received prior to being assessed for FASD, including Attention-Deficit/Hyperactivity Disorder, Bipolar Disorder, Oppositional Defiant Disorder, Learning Disabilities, and Anxiety Disorders. Caroline, an adoptive mother to a son suspected of having FASD, indicated that despite her persistence she was unable to obtain a diagnosis for her son: "I took him to a lot of different doctors trying to find out what the problem was and to get him help, and [the doctor] says there's nothing wrong with him." Six parents expressed frustration that professionals have a lack of understanding of FASD, stating that their children were often labelled as being "bad" or "defiant" without any further assessment to detect possible underlying issues. As a result, parents in this study often struggled to get a formal diagnosis for their children.

**Secondary disabilities.** Without a diagnosis, individuals are often unable to access the services and interventions that are effective in targeting secondary disabilities (Chudley et al., 2007). As a result, many adults will face adverse life outcomes, such as trouble with the law, confinement, and dependent living. In considering the numerous hardships encountered by adults with prenatal alcohol exposure, it is not surprising that a plethora of factors will impact their amenability to participate in research studies. Whereas many parents expressed interest in taking part in this research study, their adult children with FASD declined to participate. Parents cited

numerous reasons for which their adult children chose not to be directly involved in the research project. Some adults decided not to participate in the study because they are reluctant or unwilling to accept the label of FASD, which parents often attributed to the stigma associated with the diagnosis. Other individuals did not want to complete the battery of standardized tests because they had a negative experience with the diagnostic process and psychological testing in the past. Audrey, an adoptive mother to Serena, explained how her daughter's frustration with the assessment procedure interfered with receiving a diagnosis:

She never got a formal diagnosis. I took her to a doctor in southern Ontario and he was going to diagnose her and she got mad in the middle of the appointment and stomped out and said he had more problems than she did.

Along the same vein, some parents did not want their adult child to participate in the research study for fear that the testing process would be too challenging and would therefore have a negative impact on their child's self-esteem. Finally, some parents reported that they were uncertain of the whereabouts of their child, yet were still willing to participate in the qualitative component regarding the family experience.

A second challenge encountered was the retention of participants. While some parents and individuals with prenatal alcohol exposure expressed willingness to take part in the study, they were unable to participate due to competing commitments or unexpected crises. Although a considerable effort was made to accommodate the availability of families, some participants ultimately had to withdraw. In the majority of cases, sample attrition was associated with unexpected changes in the life of the individual with FASD, such as sudden unemployment, having to attend court-mandated community service, or difficulty locating the individual as a

result of numerous changes in their living arrangements. In fact, many parents expressed the difficulty in planning ahead, stating that they never knew what to expect in the future.

### **Employing Appropriate Measures**

Beyond the challenges of implementing research with individuals with FASD, special considerations must be taken in the research design when conducting studies with individuals who have developmental disabilities (Irvine, 2010). Primary disabilities associated with prenatal alcohol exposure such as impairments with memory (Green et al., 2009; Rasmussen, 2005), sensory deficits (Jirikowic, Olson, & Kartin, 2008b; Wengel, Hanlon-Dearman, & Fjeldsted, 2011), receptive and expressive language (McGee, Bjorkquist, Riley, & Mattson, 2009; Wyper & Rasmussen, 2011), difficulty with concepts relating to time (Green, 2007; Malbin, 2004), tendency to confabulate (Fast & Conry, 2004; Kully-Martens, Pei, Job, & Rasmussen, 2012b), and the ability to understand abstract concepts (Malbin, 2004) can affect the outcome of psychological measures (Finlay & Lyons, 2001; Irvine, 2010).

In conducting this study, one of the challenges that emerged was whether to administer self-report measures individually or with parent-child dyads. The Level of Service Inventory – Revised (LSI-R; Andrews & Bonta, 2001), which assesses the risk of recidivism, is a structured interview that asks individuals to think back on the past year and report whether or not they engaged in certain behaviours, such as missing work as a result of substance use. However, as noted previously, some individuals with FASD may have difficulty answering questions that are abstract in nature or make a reference to a specific timeframe. Isabelle, a 38 year-old woman with FAS, demonstrated great difficulty estimating the length of time she spent in relationships or in different occupations during the qualitative interview. Lauren, her adoptive mother, often

questioned Isabelle's responses and offered clarification that she had spent 3 or 4 years working at one job, not 8 years as her daughter had indicated. Furthermore, Isabelle often got her dates confused and had difficulty remembering whether an event occurred in 2000 or 2003. As demonstrated by this example, the inclusion of parents in interviews can serve as a source of collateral information to ensure that the information provided is as accurate as possible.

Although the LSI-R is meant to be administered individually, there are some problems with this approach when this measure is used with individuals with FASD. Most notably, individuals with FASD may have primary disabilities that interfere with their ability to be accurate historians. It is essential to use collateral file information when scoring the LSI-R; however, some individuals may not have access to official reports from the criminal justice system, employment records, or bank statements. The reliability and validity of measures such as the LSI-R can therefore be improved by including parents in the process (Irvine, 2010). The caveat to using this modification, however, is that it may compromise the privacy of the interview and may affect the way the individual will answer the question. Nevertheless, the risk of this type of corollary is minimal since most parents or caregivers are heavily involved in their adult child's life as they still require strong supports and advocacy (Olson, Oti, Gelo, & Beck, 2009; Salmon, 2008).

### **Discussion**

As research has shifted the focus of FASD from a paradigm that is medical in nature to one that considers the psychological, social, educational, and economic impact of prenatal alcohol exposure, it has become increasingly evident that there is a need to address the methodological challenges that have permeated existing literature. Drawing on the compendium

of research on FASD as well as the author's experience in conducting a mixed methods study, this paper has highlighted some of the prevalent challenges that are at the forefront of current scientific research.

In response to the challenge of recruiting participants with FASD, researchers have often relied on clinical samples. However, this approach has several limitations. First, using clinical samples may result in a bias because individuals who access supports and services typically have significant deficits that necessitated clinical attention (Kully-Martens et al., 2012a). As a result, the findings from studies employing clinical samples may not be generalizable to a broader population of individuals prenatally exposed to alcohol. Second, rural and northern communities have a higher prevalence of FASD (May et al., 2009), yet these regions remain underserved by clinical services and participants with a formal diagnosis are therefore harder to recruit (Legge, Roberts, & Butler, 2000; McFarlane & Rajani, 2007; Roberts & Nanson, 2000). Consequently, their experiences are not fully represented in current research. Third, the lack of consistency in the terminology used across studies creates heterogeneity in the sample characteristics and constructs being measured, making it difficult to compare the findings from one study to another (Arenson et al., 2010).

To address the methodological challenges related to sample size and characteristics, there is a need for more research studies recruiting participants from the general community rather than from clinical agencies (McLennan, 2010). Given the difficulty for researchers to access a large sample directly from the community, there is a need for an integrative and collaborative approach between researchers and community organizations. Some multinational databases have already been established, allowing for research with larger sample sizes while simultaneously addressing the issue of inconsistent terminology (Arenson et al., 2010; May et al., 2009).

Partnerships with community agencies are imperative, particularly when studying populations that are hard to reach (Benoit et al., 2005). As Benoit and colleagues (2005) emphasize, the benefits of such collaborations are mutual with research being improved by the availability of larger sample size and community agencies profiting from the knowledge produced from scientific studies.

One of the possible barriers in conducting community-based research is that individuals exposed to alcohol prenatally may not have a formal diagnosis of FASD, particularly when studying an adult population (Chudley et al., 2007). As mentioned previously, there are many obstacles related to the diagnostic process that may have interfered with an individual's ability to obtain a diagnosis, such as unavailability of diagnostic clinics, the multitude of changes to the diagnostic criteria, and the developmental changes that make it difficult to identify the physical features of FASD (Chudley et al., 2007; Streissguth et al., 1991). Until there is a larger sample of adults with FASD from which to draw on for future research, current studies may have to focus on adults with prenatal alcohol exposure for exploratory studies. Furthermore, adults with FASD often experience secondary disabilities that make them more difficult to recruit. Respondent-driven sampling in which individuals known to the researcher or participants are contacted directly may improve recruitment and subsequently increase sample size (Benoit et al., 2005). Regardless of the inclusion criteria and recruitment method employed, researchers should be specific in their descriptions of the sample and sampling methodology (Okazaki & Sue, 1995).

Another methodological challenge faced by researchers and clinicians alike is the paucity of measures that are sensitive to the primary and secondary disabilities associated with FASD (Chudley et al., 2005). Methodological designs that do not use appropriate measures run the risk of producing results or interpretations that are misleading or misrepresentative of the individual's

strengths and vulnerabilities (McLennan, 2010). Although the risk of generating misleading data can be circumvented by using measures endorsed specifically for individuals with FASD, the measures that have been identified as appropriate only span across specific domains such as cognitive functioning, executive functions, and adaptive behaviour (CanFASD Northwest, 2007; Chudley et al., 2005). Consequently, it may be necessary to refer to corroborative sources and file information when appropriate measures are not yet available (Kully-Martens et al., 2012a; Schonfeld et al., 2006). At times, the inclusion of external sources of information may involve deviating from standardized protocol; consequently, it is important that the benefits of such modifications outweigh the risks. Furthermore, any divergence from standard procedure should be clearly documented in the description of the methodology employed.

The majority of the recommendations presented thus far have been geared towards improving quantitative studies; however, it is important to recognize the need for qualitative research on FASD (Jirikowic et al., 2008a; Olson et al., 2009; Watson, Coons, & Hayes, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). Recently, studies on families of children with disabilities are incorporating a qualitative component to address the limitations of quantitative measures that do not provide participants the opportunity to fully capture their perspectives (Esdaile & Greenwood, 1995; Watson, Hayes, & Radford-Paz, 2011). Unlike quantitative measures that are close-ended and require participants to select from a list of preselected responses, qualitative research allows individuals with developmental disabilities to have a voice that is representative of their experiences (Irvine, 2010). This approach is particularly beneficial in exploratory studies where the factors associated with a particular variable have yet to be well-established.

Methodological challenges notwithstanding, research on FASD has many advantages. In addition to improving our understanding of FASD, empirical evidence also plays a central role in the development of policies and recommendations that have a positive impact on the lives of individuals with this condition (Astley et al., 2009; Badry & Felske, 2010; Salmon & Clarren, 2010). Furthermore, families expressed gratitude to the researcher for having the opportunity to share their story in the hopes of having a positive impact on families undergoing similar challenges.

Ongoing research on FASD is therefore an endeavour that has important implications for families, researchers, policy-makers, and clinicians. As such, the identification of the common difficulties encountered when conducting research studies on FASD can help prevent such challenges in future research in order to improve the overall quality of scientific studies.

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Running Head: Families' Perspectives

**“He’s on the streets, and stealing and perpetuating the cycle... and I’m helpless”: Families’  
perspectives on criminality in FASD**

Elisa Radford-Paz

Laurentian University

### **Abstract**

Despite the high rate of criminality in adults with Fetal Alcohol Spectrum Disorder (FASD), little is known about the risk and protective factors associated with criminal behaviour in this population. The purpose of this qualitative study was to explore the family experience of adults with prenatal alcohol exposure (PAE) to better understand the factors that increase or decrease criminality. Families identified four risk factors that contributed to their adult child's trouble with the law, including difficulty with self-regulation, negative influences from the peer group, substance use, and multiple transitions. Protective factors that were reported to help mitigate the effects of the legal issues were structure and supervision, educational and occupational success, access to clinical and financial support, and having a strong network of positive influences. The findings from this study emphasize the need for more family-centred interventions to improve the outcome for adults with PAE.

**“He’s on the streets, and stealing and perpetuating the cycle... and I’m helpless”:**

### **Families’ perspectives on criminality in FASD**

The teratogenic effects of alcohol cause lifelong physical, cognitive, and behavioural impairments that are collectively called FASD. As many as 60% of individuals with FASD will experience trouble with the law (Streissguth, Barr, Kogan, & Bookstein, 1997) and systematic studies have established that individuals with FASD are 19 times more likely to be incarcerated than members of the general population (Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011). Although current models of criminality in FASD emphasize the poor fit between an individual’s capabilities (e.g., neurocognitive impairments) and the environmental demands (e.g., multiple transitions, lack of structure; Brown, Connor, & Adler, 2012; Malbin, Boulding, & Brooks, 2010), few studies have examined the specific risk and protective factors associated with the family system and the psychosocial milieu of the individual. The aim of this qualitative study is to explore the risk factors and protective factors associated with criminality identified by families of adults with PAE.

### **Fetal Alcohol Spectrum Disorder**

Prenatal exposure to alcohol can cause a myriad of lifelong impairments such as growth deficiency, facial dysmorphology, and dysfunction of the central nervous system (CNS; Astley & Clarren, 2000; Streissguth et al., 1997). The umbrella term FASD encompasses a continuum of medical diagnoses, including fetal alcohol syndrome (FAS), partial FAS (pFAS), and alcohol-related neurodevelopmental disorder (ARND). The prevalence of FASD in Canada is 9.1 in 1000 live births (Health Canada, 2006), while the prevalence of FASD in the United States and Western Europe has been estimated to range from 2% to 5% of the population (May et al., 2009).

FASD is considered to be the leading preventable cause of intellectual disability in North America (O'Leary et al., 2012).

Although the direct mechanism whereby alcohol affects the developing fetus remains unclear, the permanent teratogenic effects of alcohol have been well documented (Riley & McGee, 2005). Factors such as the quantity of alcohol consumed, the number of exposures to alcohol as well as timing of exposure, individual differences in the tolerance of alcohol, poor nutrition during pregnancy, and exposure to other intoxicants can affect fetal development (Astley & Clarren, 2000). While the neurobehavioural phenotype associated with gestational alcohol exposure is in large part dependant on an array of factors, there is extensive evidence that PAE leads to cognitive and behavioural impairments, termed "primary disabilities", even in the absence of physical characteristics (Connor, Sampson, Bookstein, Barr, & Streissguth, 2000; Mattson, Riley, Gramling, Delis, & Jones, 1998; Rasmussen, 2005). Primary disabilities are congenital impairments caused by PAE that are attributed to organic brain damage and are therefore presumed to be irreversible (Streissguth et al., 1997). There is a wealth of research that suggests that individuals with FASD have significant impairments in executive functioning (Pei, Job, Kully-Martens, & Rasmussen, 2011; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008; Vaurio, Riley, & Mattson, 2011), adaptive behaviour (Brown et al., 2012; Carr et al., 2010; Schonfeld, Paley, Frankel, & O'Connor, 2006), academic abilities (Godel et al., 2000; Rose-Jacobs et al., 2012), and social skills (Kelly, Day, & Streissguth, 2000; Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012).

In addition to the primary disabilities associated with CNS dysfunction, individuals with FASD are exposed to adverse environmental factors postnatally such as exposure to trauma, instability in the home environment, living in an impoverished environment, and inconsistent

parenting styles (Henry, Sloane, & Black-Pond, 2007; Olson, O'Connor, & Fitzgerald, 2001; Kalberg & Buckley, 2007). Furthermore, only 20% of individuals with FASD reside with their biological mothers (Astley, Bailey, Talbot, & Clarren, 2000; Streissguth et al., 2004). Individuals with FASD are particularly vulnerable to environmental challenges as a result of the CNS impairments caused by prenatal alcohol exposure (Page, 2002). When cognitive and behavioural impairments are accompanied by an adverse environment, the interaction of these vulnerabilities may lead to the development of additional problems, labelled "secondary disabilities" (Streissguth et al., 1997). Without appropriate interventions, individuals with FASD may face secondary disabilities including mental health disorders (90%), disrupted school experience (61%), legal problems (60%), and confinement (50%; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Streissguth et al., 2004).

Historically, research has sought to delineate the risk factors associated with secondary disabilities in FASD, yet few studies have examined the protective factors that contribute to positive life outcomes. One longitudinal study identified a host of protective environmental factors for individuals with FASD, including having a stable and nurturing home environment, having basic needs met, never experiencing violence, receiving a diagnosis of FASD before the age of six, receiving a diagnosis of FAS, and receiving supports and services (Streissguth et al. 1997; 2004). Furthermore, Canadian researchers have noted that factors such as having stable employment, having a strong social network, having access to supports and services, and living independently may help reduce the effects of secondary disabilities for adults with FASD (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008). Taken together, the findings from previous research suggest that although individuals with FASD have biological predispositions that cannot be altered (i.e., primary disabilities), the presence of protective factors can help prevent the

emergence of adverse life outcomes such as criminality and incarceration (i.e., secondary disabilities).

### **Criminality in Individuals with FASD**

Individuals with FASD are overrepresented in the criminal justice system (Burd, Selfridge, Klug, & Juelson, 2003; Fast, Conry, & Loock, 1999; Popova et al., 2011). It is estimated that 60% of individuals with FASD will experience trouble with the law in their lifetime (Streissguth et al., 1997). A systematic review of studies on the prevalence of FASD in the Canadian criminal justice system found that in comparison to the general population, individuals with FASD were 19 times more likely to be incarcerated (Popova et al., 2011). In a study conducted in British Columbia, Canada, a cohort of 287 incarcerated youth between the ages of 12 and 18 were ordered to undergo forensic psychiatric or psychological assessment. The researchers found that of the individuals screened, 23.3% met the criteria for a diagnosis of FASD; however, only 1% had been diagnosed prior to the mandated assessment (Fast et al., 1999). The findings from this study suggest that many individuals with FASD are undiagnosed prior to their involvement with the criminal justice system and are therefore precluded from accessing the supports and interventions that could help reduce the likelihood of criminality.

The primary disabilities experienced by individuals with FASD often lead to higher rates of problematic behaviour, such as lying, cheating, disobedience, and stealing, which could put them at increased risk of engaging in delinquent acts (Nash et al., 2006). Furthermore, impulsivity (Schonfeld et al., 2006), aggression (Brown et al., 2012), difficulty understanding social cues (Kully-Martens et al., 2012), and limited understanding of cause and effect (Fast & Conry, 2004) create a susceptibility to peer pressure and victimization, violation of rules, and

understanding the consequences of their actions (Brown et al., 2012; Chudley, Kilgour, Cranston, & Edwards, 2007; Clark et al., 2004). Whereas behaviours that violate social norms are typically ascribed to anti-social attitudes and defiance, in the case of FASD there is strong consensus among researchers, clinicians, and policy-makers that the challenging behaviours exhibited by individuals with FASD are not willful but rather a consequence of neuropsychological deficits (Brown et al., 2012; Malbin et al., 2010; Moore & Green, 2004; Rasmussen & Wyper, 2007). Indeed, it appears that the majority of criminal acts perpetrated by individuals with FASD are reactive and opportunistic rather than premeditated and planned (Brown et al., 2012).

Malbin and colleagues (2010) proposed a neurobehavioural model of criminality in FASD in which neurobehavioural deficits are regarded as important contributors to criminal activity as a result of a poor fit between the individual's abilities, their environment, and the expectations placed upon them. Rather than focusing on effecting changes at the intrapersonal level, proponents of the neurobehavioural model argue that effective treatment for offenders with FASD necessitates accommodations geared towards the individual's unique needs as well as their strengths (Burd, Fast, Conry, & Williams, 2010; Fast & Conry, 2009; Malbin et al., 2010; Page, 2002). By increasing the congruence between the individual's neurobehavioural profile and the environmental demands, a preventative approach based on skill building and the increase of protective factors can be employed to mitigate the impact of secondary disabilities such as trouble with the law (Henry et al., 2007).

**The Family Experience: Giving families a voice**

Streissguth and colleagues (2004) found that the caregiving environment had a substantial impact on the outcome of individuals with FASD. Nevertheless, few studies have examined the experience of families of children with FASD to better understand the specific challenges and stressors that may impact the home environment (Olson, Rudo-Stern, & Gendler, 2011; Watson, Coons, & Hayes, 2013). The bulk of research has examined the impact of raising a child with FASD through the lens of parenting stress. Researchers have consistently found that parents of children with FASD experience high levels of stress on a variety of measures of parenting stress (Jirikowic, Olson, & Astley, 2012; Olson, Oti, Gelo, & Beck, 2009; Paley, O'Connor, Frankel, & Marquardt, 2006; Paley, O'Connor, Kogan, & Findlay, 2005; Watson et al., 2013). A study examining parenting stress in 42 biological mothers of children with FASD found that higher levels of child externalizing behaviours (e.g., aggressive, oppositional, or defiant behaviour) and lower levels of parental support predicted greater maternal stress (Paley et al., 2005). A subsequent study conducted with both biological and adoptive parents found that increased levels of parenting stress were associated with greater child externalizing behaviours, internalizing behaviours (e.g., anxious or depressed behaviour), and larger impairments in executive functioning and adaptive behaviours (Paley et al., 2006).

Similarly, qualitative studies have identified stressors reported by parents, including difficulty providing safety for their children and managing challenging behaviours (Caley, Winkelman, & Mariano, 2009), fear for the child's future (Gardner, 2000; Watson, Coons, Hayes, & Radford-Paz, in press), and lack of formal and informal supports (Brown & Bednar, 2004). Collectively, studies on parenting stress suggest that caregiving stress is associated with dysregulated behaviour in children and a lack of support and resources for families (Jirikowic et

al., 2012). While research has focused on the stressors faced by caregivers of children with FASD, little is known about the factors that contribute to resiliency and positive life outcomes. Furthermore, there is a marked need for qualitative research in order to include the voice of families in research on FASD with the goal of gaining an understanding of their experiences (Olson et al., 2011; Watson et al., 2013).

### **Methodology**

A qualitative study consisting of semi-structured interviews was undertaken to explore the factors associated with criminality in adults with PAE. This study was approved by the Laurentian University Ethics Board, in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants.

### **Participants**

Participants were recruited from various FASD parent support groups across Ontario, Canada employing a convenience sampling technique. Thirty-three online support groups were contacted via e-mail inviting families who were interested in participating in the study to contact the researcher by telephone or e-mail. Individuals known to the researcher were also contacted and invited to participate in the study. This sampling technique, called respondent-driven sampling, is commonly utilized with hard-to-reach populations (Benoit, Jansson, Millar, & Phillips, 2005). Eight families from Ontario, Canada, participated in this study. In order to participate, caregivers had to have at least one adult child, 18 years of age or older suspected of having FASD. One biological mother, five adoptive mothers, and two custodial grandmothers were included in the study (herein referred to as parents or caregivers). The age of the adult

children ranged from 19 to 42 years, with an average age of 29.8 years. Six interviews were conducted with only the caregiver present, while two interviews consisted of parent-child dyads.

### **Interviews**

The semi-structured interviews employed a basic interpretive qualitative approach, which seeks to understand how individuals interpret and make sense of their lived experiences (Merriam, 2002). This methodology is grounded on the principles of phenomenology and symbolic interactionism and provides a richly descriptive account of the individual's perspective of a situation. As a result, the inclusion of a qualitative approach allows the researcher to gain a deep understanding of the experience from participants' perspectives (Merriam, 2002). The semi-structured interviews consisted of a blend of less and more structured questions, such as "How would you characterize your child's relationship with the law?" and "Can you describe any strategies or supports you used to help you deal with your son/daughter's challenging behaviours?" The questions for the interviews were based on the universal risk and protective factors identified in previous research (Streissguth et al., 1997; 2004). The interviews were conducted in a location chosen by the participants, such as the families' homes or a coffee shop. The length of the interviews ranged from 45 minutes to two hours. With permission of the participants, interviews were digitally recorded to allow for subsequent transcription. To protect participant confidentiality, all names and identifying information have been changed.

### **Data Analysis**

Interviews were analyzed using interpretive phenomenological analysis (Storey, 2007) whereby verbatim transcripts of the interviews are reviewed several times in order to identify general themes spoken by parents. This analysis aims to capture the meaning participants ascribe

to their experiences, as well as how the protective factors identified by families impact the risk of criminality in adults with PAE. The systematic process of analysis begins with recording general comments in the margins and gradually involves identifying commonalities in participants' experiences and overarching themes (Smith & Eatough, 2007). Families were given the opportunity to ensure that their words were not misrepresented.

## **Results**

The cognitive and environmental factors associated with criminality in adults with PAE can be categorized along two dimensions: risk factors that increase the likelihood of criminality and protective factors that decrease the probability that an individual will experience trouble with the law. The qualitative analysis of the semi-structured interviews yielded four superordinate themes related to criminality: difficulty with emotional and behavioural self-regulation, having a negative peer group, substance use, and multiple transitions. In terms of protective factors, the four superordinate themes identified were the importance of structure and supervision, the need for education and employment that is compatible with the individual's strengths and vulnerabilities, having positive influences. Each theme and the corresponding subthemes are discussed in detail to provide an overall picture of families' perspectives of the risk and protective factors associated with criminality in adults with PAE.

### **“It felt like a tornado was in the house”: Emotional and behavioural self-regulation**

Families attributed their adult children's involvement with the law to underlying difficulties with self-regulation and inhibitory control. The behaviours reported by parents were consistent with the “fight or flight” response, whereby individuals with PAE responded to challenging situations in impulsive and reactive manners, characterized by episodes of

uncontrollable rage or by running away from demanding situations. In particular, aggression and impulsivity were described as subthemes that fall under the umbrella of emotional and behavioural self-regulation. While aggressive outbursts may have been managed by parents during childhood, episodes of violent behaviour became increasingly difficult to manage when individuals reached adolescence and adulthood. In the same way that the aggressive outbursts were conceptualized by families as reactive rather than intentionally malicious, parents also discussed how their adult children's criminal behaviour was often associated with impulsivity and difficulty understanding abstract concepts such as ownership. Consequently, criminal acts such as theft were described as a byproduct of the individual's primary disabilities rather than a premeditated act.

**“He had uncontrollable rages”:** **Aggression.** Emotional dysregulation was a predominant concern for families of individuals with PAE. Seven of the eight families reported that regardless of their child's age, there was a lifelong pattern of poor frustration tolerance and impaired ability to regulate emotions. These seven families described violent outbursts that involved death threats, physical assaults, the use of weapons, and destruction of property. In many cases, the intensity of the aggressive episodes warranted police involvement to keep the individual and family members safe from harm. As Caroline, adoptive mother to Noah, explains, “He would threaten to kill our daughter. That was when he first became involved with the police. Threatened to kill us... we had to call the police sometimes because he wouldn't, he wouldn't calm down.” Similarly, Emma, a custodial grandmother, described the aggressive behaviour displayed by her 22 year-old grandson: “[H]e was physically violent... my bedroom door, it has holes in it from when he was swinging a skateboard at the door. He threatened me with knives.”

Many families struggled to contain their child's aggressive behaviour, particularly in adolescence and adulthood. Caregivers reported feeling helpless during episodes of "explosive" anger, stating that they were often unable to fully understand the source of their child's distress and subsequently struggled to help their child de-escalate and return to a calm state. When asked to identify the most difficult part of managing her children's offending behaviour, Sadie, an adoptive mother to two children with PAE, expressed, "I guess just feeling helpless, you know? You try and whatever you do doesn't seem to work."

**"I don't think about consequences": Impulsive behaviour.** The title of this theme, spoken by Isabella, a 38 year-old adult with FAS, captures the primary disabilities that interfere with the ability to regulate behaviour. Families described how poor inhibitory control, coupled with difficulty understanding the consequences of actions, can lead to delinquent behaviour that is reactive in nature. In fact, every account of offending behaviour reported by the families in this study was opportunistic and impulsive, not having been planned beforehand. Gavin, a young man with FAS, explained how impulsivity and difficulty in understanding abstract concepts such as ownership and morality contributed to his criminal behaviour:

I guess when I was younger I didn't realise the consequence of ownership type of thing so I tend to sometimes go into people's house and be like 'oh that's shiny, that's nice' and I would take it and I wouldn't really feel... bad about it and then I would go in the grocery store or something and say 'I want that but I don't have any money, yoink!'

Parents expressed tremendous concern regarding their ability to keep their child safe because of the impulsivity that is inherent to PAE. Lauren, a biological mother to Isabelle, described how impulsivity made it difficult to predict her daughter's behaviour and therefore

prevent criminal acts. Furthermore, the difficulties with behavioural regulation led to chaotic environments in which structure may have been lacking. Families explained that impulsivity also contributed to their child`s tendency to abscond in distressing situations. Some parents indicated that they were uncertain of the extent to which their child was involved with the law since they often faced extended periods of time in which they were unaware of their child`s whereabouts because of their tendency to run away from home.

**“Needed to belong, needed to be accepted”: Peer group**

In addition to impairments in self-regulation, families also reported that social difficulties contributed to delinquent behaviour in individuals exposed to alcohol prenatally. Some of the neurobehavioural deficits associated with PAE such as impulsivity and difficulty understanding social cues can lead to rejection and alienation by peers. In the first subtheme, lack of friends, families discussed the isolation experienced by their children, starting from a young age and extending well into adulthood. Nevertheless, when this social isolation is juxtaposed with a strong desire to belong to a peer group and to gain acceptance by others, it becomes evident that individuals with PAE can be susceptible to negative peer influences. In the second subtheme, all caregivers spoke of their child`s peer group in terms of their vulnerability to negative peer influences, particularly when it comes to criminality. The majority of families reported that their children associated with peers engaging in activities such as truancy, substance use and criminal activity.

**“He never fit in”: Lack of friends.** A subtheme that emerged from the interviews related to the challenges with interpersonal relationships faced by individuals with PAE. Parents contended with the fact that their children often experienced rejection by their peers. Although

social isolation started at a young age for many individuals with PAE, parents also described the challenge of seeing their child struggle with interpersonal relationships. Caroline, an adoptive mother to a 22 year-old son with PAE, stated:

[H]e seems to have friends for a while, and all of a sudden they disappear and we don't know why. He said to me the other day 'I decided all my friends are, they're not really my friend except for two.' One was a girl that we've met once. And the other was a guy that we haven't seen for maybe two years now.

Previous research has hypothesized that impairments in social skills may interfere with the ability to establish and maintain positive relationships (Kully-Martens et al., 2012). In particular, impulsivity, disregard for boundaries, hyperactivity, and disruptive behaviour may lead to rejection by well-adjusted peers. Without a positive peer group to turn to, individuals with PAE are vulnerable to negative peer influences. As Kate, adoptive mother to a son with FAS explained, "And a lot of the kids that succeed are like that. They're very, very, very isolated because they're trying to stay away from the dangerous places. But they don't have anywhere else to go. Nobody wants them around."

**"They're hanging around the kids who got in trouble": Negative influences.** Parents also expressed concern that their children's social difficulties, combined with a desire for acceptance and belonging, resulted in interactions with a negative peer group. Families observed that peers who typically befriended individuals with PAE do not value appropriate social behaviour; rather, they tend to engage in behaviour that is "anti-social", such as substance use, truancy, and criminality. Sadie, whose adoptive daughter Maria was part of a peer group involved in criminal activity, stated: "She certainly wasn't learning appropriate behaviors as to

how to get along in society.” Six parents noted that their children’s criminal behaviour occurred in the presence of peers and families expressed concern that their children’s criminality was influenced by their group of friends. Leah, a biological mother to Noah, worried that involvement in the criminal justice system exposed her son to a group of peers who have a history of criminality, thereby compounding the effect of the negative peer group. Another concern voiced by parents was that peer pressure often led to other high risk behaviour, such as drug use. The two parents in this study who did not discuss the negative peer group as a contributing factor to criminality had nevertheless stated that their children had engaged in substance use as a result of influences from their friends. Although substance use is not typically considered to be a criminal act in research, it can often lead to legal issues in individuals with PAE.

#### **“It’s a battle every day”: Substance use**

The contribution of substance use to offending behaviour was noted by seven families. Parents explained that their child’s involvement with the law often occurred as a result of intoxication related to alcohol, drugs, or a combination of the two. In the case of Dawson, a 35 year-old man with PAE, criminality was a way to support his addiction. Sadie, his adoptive mother, explained how substance use led to her son’s involvement with the law:

He was a mess. He was doing drugs, prostituting himself to get drugs. He just trashed his apartment. He was living with a friend from up here actually and he just trashed it. I guess, well he was on drugs, really trashed it, supposedly about \$4,000 damage so his roommate had to call the police and the police came.

Three parents expressed concern that substance use also served as a gateway to other dangerous behaviour, such as stripping, prostitution, and stealing. Furthermore, Lauren stated that substance use interfered with her daughter Isabelle's ability to maintain steady employment and avoid trouble with the law. One particular challenge faced by six families in this study was that their child's substance use began between the ages of 9 and 14 years. Of these six parents, five reported that they are still concerned about their adult child's drug or alcohol consumption. Consequently, substance use appears to be a lifelong battle for many adults with PAE and an important risk factor for criminality.

#### **“It was just a continuous chaos”: Multiple transitions**

A final contributing factor to criminality discussed by parents was the lack of structure related to multiple transitions. Five families reported that their children often moved from one household to another, rendering it difficult to have a stable and consistent home environment. For some individuals with PAE, changes in the home environment may include a combination of living with biological, foster, and/or adoptive families. Furthermore, living milieus may also include residential treatment centres, juvenile detention centres, and jail. In addition, some families reported that their children would reside with a multitude of friends for extended periods of times, not having a permanent household for a significant timeframe. For example, Audrey, an adoptive mother to a daughter with FAS, stated, “I don't think I'm exaggerating if I say she lived in 20 different places between the ages 13 and 20”. The lack of structure ensuing from multiple transitions often led to unsupervised time, which four families identified as a contributing factor to criminality for individuals with PAE. Furthermore, Caroline indicated that she is unaware of the full extent of her adoptive son's legal problems because of the multiple transitions that he has experienced: “So we ended up kicking him out of the house... He couch surfed for a while. And

he had, see there could be all sorts of times when he was involved with the police that we don't know about."

### **“His behaviour is not going to change until you change his environment”: Structure and supervision**

In line with research conducted by Streissguth and colleagues (1997; 2004), adverse life outcomes can be examined from the point of view of risk factors as well as protective factors. Although families identified risk factors that contributed to their adult child's involvement with the law, caregivers also spoke at length about the protective factors that helped decrease the likelihood that their child's primary disabilities would result in criminality. A major recurring theme with regards to protective factors was the need for structure in the day-to-day life of individuals with PAE. Given the deficits with executive functioning found in individuals with FASD, many individuals are incapable of organizing their environment to provide structure (Clark et al., 2008). Thus, the structure must be imposed externally, typically by parents (Clarren, 2000). In fact, six parents attributed their children's success to structured environments, stating that their children thrive in environments in which they do not have to engage in planning or organize their time. As discussed previously, transitions are very difficult for individuals with PAE. For this reason, structure can help individuals with PAE know what to expect throughout the day. Tara, an adoptive mother to a son with FAS, noted the importance of having an environment that is structured:

So it was always this fine line of saying what his needs are and people saying you're not letting him take enough risk, or you're not letting him um, you're enabling him and not empowering him. But in the long run... Like we're sitting here today saying all the risks I

didn't let him take. The fact that he hasn't had a criminal record is because he was, we contained his environment.

Along the same vein, three parents discussed the importance of supervision to protect their children from adverse life outcomes. According to parental accounts, many instances of criminal activity occurred when there was little to no structure and a lack of adult supervision. Five families reported that they were better equipped to manage their children's behaviour once they understood that their conduct was not willful or manipulative, but rather a consequence of the CNS dysfunction caused by the teratogenic effects of alcohol.

Three parents discussed the challenge of providing supervision once their adult children moved to a different city for post-secondary studies or employment. Three families enlisted the help of caregivers to be able to provide the structure and support with daily living skills their adult children required. Thus, one of the lifelong challenges faced by families of children with PAE was striving for interdependence instead of independence, which entails greater emotional, social, and financial support for daily living (Clark et al., 2008).

**“If he had been able to get an education then I think he'd be able to be a functioning member of society”: Education and Employment**

Many individuals with PAE are unable to meet the demands in educational and vocational settings (Streissguth et al., 1997); consequently, they are often faced with a lot of unstructured time in adolescence and adulthood. However, five parents spoke of the importance of having activities that provide social connections within a structured setting. As Kate, an adoptive mother to Cody, stressed, “He's always looking for work because the biggest, biggest thing that we would notice is that filling his spare time is essential, that he cannot have spare

time..."Although these five parents noted that there were challenges in finding employment tailored to the needs and strengths of the individuals, families also emphasized the positive impact that education and employment has on the well-being and self-esteem of their children.

Sadie, an adoptive mother to Maria, discussed the successes her daughter has experienced:

Yeah she has her own shop. Actually it's in a senior's building and so many of her clients of course are seniors and they just love her, they think she's just really great. One thing that I have noticed is that she's slower at doing hair, you know, than what you'd expect when you went into say another salon that caters to all ages. But she's very efficient, you know, and does the job well.

Parents reported that their children experienced more positive outcomes when the emphasis was placed on their strengths rather than their vulnerabilities. Although school was a challenge for most individuals with PAE, three parents stated that their children had greater success in environments that focused on practical skills instead of academic abilities. As a result, six families expressed the critical need to build a partnership with teachers and principals in order to support the specific needs and learning styles of individuals with PAE.

### **"They really wanted him to succeed in this endeavor and not end up in jail": Supports**

Beyond the strategies employed by parents to support their children, families also emphasized the importance of having access to clinical and financial supports in order to mitigate the effects of secondary disabilities. Although there was overwhelming consensus among families that the services available were insufficient to adequately meet the needs of individuals with PAE and their family members, caregivers remained appreciative for the assistance they had received. In part, families spoke of the programs that were available to assist

their children in gaining their independence in adolescence and adulthood. However, parents also spoke of the importance of having supports for family members to counteract the feelings of hopelessness, frustration, and isolation experienced by parents of individuals with PAE.

**“They really wanted him to be safe. It was nice, it was a miracle”:** **Supports for individuals with PAE.** A primary concern raised by parents was the ability to support their children in the transition to a more independent lifestyle in adulthood while simultaneously ensuring their safety. Given the dearth of FASD-specific supports, all parents were faced with the challenge of finding services that are suitable to their child’s unique vulnerabilities, including individual counseling, residential programs, child and youth workers, and summer camps. The majority of parents reported having to look beyond community supports to find adequate services, often paying out of pocket. Regardless of the modality of the support provided, four parents reported that the greatest impact was felt when adaptive behaviours were targeted. More specifically, services aimed at remediating social skills and daily living skills had the greatest impact in terms of preventing delinquent behavior. As Tara, an adoptive mother to a son with FAS, explained:

He’s always had a worker to help him with um, either daily living skills or community involvement. He still has the special services home worker. She helps him with their dishes and laundry and cleaning the apartment. So Gavin’s grown up learning to be interdependent. So he never had somebody say to him oh you’re 16 you should be able to do this. He never had those kinds of comments.

By striving for interdependence rather than independence, parents were able to balance their child’s need for autonomy and their need for safety. Furthermore, improving social skills helped

individuals with PAE integrate more easily into peer groups that provided more positive influences.

**“That helps because you know you’re not the only one”: Supports for the family.** In addition to having supports for the individual with PAE, all parents also spoke of the importance of having supports for family members. Five parents expressed that formal supports such as parent support groups helped them feel less isolated and hopeless. The benefits of formal supports for families described by parents were twofold; first, the supports provided an avenue in which caregivers could learn strategies or techniques that helped them respond to their child’s behaviour more effectively, and second, it also helped them share their experiences with other families who truly understood what it was like to raise a child with PAE. Parent support groups allowed parents to shift from a framework of accountability of behaviour and shame to one that takes the CNS dysfunction into account, thereby allowing parents to have more realistic expectations for their children. As Audrey, an adoptive mother to a daughter with FAS, stated:

[O]ne night [at the parent support group meeting] I shared something that Serena had done and one of the mothers whose daughter is living the exact same life that Serena did said to me jokingly, ‘when are you going to get it? That’s what these kids do!’ And we laughed. And I thought if I’d been home alone, I’d be bawling my eyes out for days. But because she really understood we laughed about it, like I couldn’t believe we laughed about this terrible situation, but it broke the pressure.

**“I just surrounded her by what I consider really positive forces”: Positive influences**

Despite the existing vulnerability to negative influences, positive peer influences can have an equally important impact on individuals with PAE. Parents reported that surrounding

their children with a strong support system that included family, friends, community groups, and advocates helped protect their child from criminality. In particular, families voiced the need for positive role models and peer groups to promote a sense of resilience and hope in individuals with PAE. Furthermore, parents often acted as a consistent positive influence in their child's life through their role as advocates. Although families faced a multitude of barriers, caregivers exemplified the positive characteristics they hoped to cultivate in their children by remaining optimistic and positive in the face of challenges.

**“They all still have issues of one kind or another but they really stick together”:**

**Positive peer group.** Six parents discussed their child's lifelong challenge of finding a positive peer group. Negative peer groups notwithstanding, two parents reported that their children's support system also included individuals with some type of disability. Three parents noted that their children benefitted greatly from summer camps designed specifically for individuals with disabilities because it provided a safe and structured environment in which they could meet individuals that were at similar developmental levels. Moreover, two families also involved their children in community-based activities, such as church groups and music programs, to foster positive social relationships in their child's life.

In addition to having a network of friends, caregivers also discussed the importance of having strong role models. Emma, a custodial grandmother, described the positive impact of surrounding her grandson by positive adult role models: “He gets invited to play [music] with the big boys, the grown-ups who have a band. And, hobby band, they'll invite him to go play with them. He gets that kind of validation.” Leah, a custodial grand-mother to Chloe, spoke of the value of surrounding her grand-daughter with role models that instilled hope that she could lead a happy, productive life: “I think surrounding her by those type of role models [helped] and

people that said to her ‘you can do anything’ and I always said that to her, ‘you can do anything you want to’.” Noting the intergenerational patterns that often precede individuals with PAE, Leah emphasized the need to disseminate the message that individuals can overcome challenges and adversity related to gestational exposure to alcohol and experiencing positive life outcomes.

**“I’ve had to be his advocate in many, many ways”:** Parents as advocates for their children. In light of the notable absence of positive role models, many parents reported that they took on the role of advocating for their children. Citing the paucity of supports and services, Leah, a custodial grandmother to Chloe, gave up her occupation and dedicated herself fully to seeking resources, educating professionals, and providing financial support for the few services available. Within the legal system, three parents reported having to find lawyers who were either familiar with the lifelong effects of PAE or amenable to learning about FASD, as well as parole officers who were willing to take their adult child’s vulnerabilities into account. Nevertheless, parents had to bear the responsibility of finding the appropriate supports and educating professionals. Kate, an adoptive mother, stressed the need to be tenacious: “And you can’t take no for an answer. Like for someone to say, ‘sorry we can’t afford that’ is absolutely an abrogation of every human being’s rights.” Through their unwavering dedication, parents hoped to protect their children from secondary disabilities by increasing awareness of FASD and thereby changing the expectations placed upon individuals with PAE by the educational and judicial systems.

### **Discussion**

The overarching theme discussed by families was the need for structure and support for individuals with PAE, regardless of their age. According to the parents in this study, individuals

with PAE face vulnerabilities that increase the likelihood of criminality. Difficulties with behavioural and emotional self-regulation, combined with environmental factors such as negative peer influences, substance use, and multiple transitions can create situations in which the demands placed on the individuals outweigh the capabilities to cope with the exigencies. The results from this study are consistent with previous research findings that individuals with PAE fare better in situations that are predictable, structured, and do not require decision-making (Brown et al., 2012; Kelly et al., 2000). The lack of consistency in routine is problematic for individuals with PAE because they often have difficulty adapting to new environments as a result of difficulty generalizing skills from one setting to another (Malbin, 2004), deficits in executive functioning relating to planning, inhibitory control, and cognitive flexibility (Kodituwakku, Kalberg, & May, 2001), as well as impairments in adaptive behaviours such as daily living skills and communication (Jirikowic, Kartin, & Olson, 2008).

Recognizing that conduct problems were related to underlying neurocognitive deficits, parents discussed the importance of being proactive instead of reactive when faced with challenging situations. Many caregivers found it difficult to help their children return to a calm state during episodes of emotional dysregulation; nevertheless, preventative strategies such as reducing the amount of transitions, identifying precipitating factors that contributed to distress, and maintaining a routine were identified as helpful strategies by families. Thus, treatment plans for individuals with FASD should delineate strategies for both the individual and the family to cope with unexpected circumstances that may arise (Brown et al., 2012).

Parental concerns with the impact of peer influences on their child's behaviour is reflective of existing research, which suggests that the majority of criminal acts perpetrated by individuals with PAE occur within a group setting and rarely occur unaccompanied (Brown et

al., 2012). Currently, offenders with FASD are sentenced in the same manner as typically developing peers despite their unique needs. Insofar as it can be ascertained, current rehabilitation and treatment models for offenders that are predicated on a cognitive approach are less effective for individuals with FASD than structured behavioural treatments targeting maladaptive behaviours (Boland, Burrill, Duwyn, & Karp, 1998; Brown et al., 2012; Page, 2002). Moreover, as parents in this study indicated, incarceration may have a detrimental effect on individuals with FASD because they are vulnerable to the influence of their peers. This vulnerability is attributed to the fact that individuals with FASD have difficulty forming friendships as a result of their primary disabilities (Kully-Martens et al., 2012). Without a positive group of friends to turn to, children with FASD have a tendency to seek social connections with negative peer groups. Thus, by placing them in a setting with other offenders, it is likely that individuals with FASD will seek a sense of belonging among other incarcerated criminals.

Families also discussed the protective factors that led to more positive outcomes for their children. In particular, caregivers reported that having a structured environment, finding educational programs or employment opportunities suited to their adult children's strengths and vulnerabilities, having access to supports and services for both the individual with PAE and the family members, and surrounding their children with positive influences were all factors that promoted well-being and decreased the likelihood of experiencing trouble with the law. The findings from this study support the neurobehavioural model, which suggests that intervention for criminality should focus on accentuating the strengths of the individual while implementing environmental modifications such as structure and routine (Malbin et al., 2010). Parents in this study reported that their adult children required lifelong supports for day-to-day living. Clarren

(2000) coined the term “external brain” to describe the role of caregivers as providers of structure and consistency to help individuals with PAE regulate their emotions and behaviour. Indeed, many researchers and clinicians highlight the need to focus on strength-based approaches and environmental accommodations (Green, 2007; Malbin et al., 2010; Page, 2002; Watson & Westby, 2003). Unfortunately, many individuals with PAE do not get diagnosed prior to their involvement with the criminal justice system (Fast et al., 1999) and therefore do not benefit from treatment or clinical services. Consequently, there is a striking need to shift the management of FASD from the judicial system to a more preventative approach that includes both mental health and educational sectors.

Although parents spoke of the importance of having supports and services, many families mentioned the financial burden associated with accessing and maintaining services for their children. Emma, a custodial grandmother, indicated that even when supports were available many families were unable to access them because they lacked the financial resources. Many times, families had to make considerable sacrifices in order to pay for services for their children. As Kate, an adoptive mother, explained, “Eventually social services refused to pay for [the carekeeper] so three weeks before he started college I had to sell my house.” Given that the caregiving environment has a significant impact on the well-being individuals with PAE and that parental stress is negatively impacted by the lack of supports, it follows that facilitating access to services is an important part of ameliorating life outcomes for individuals with FASD.

### **Limitations**

Although this study helps elucidate some of the risk and protective factors associated with criminality in individuals with PAE, there are some important limitations. Despite efforts to

recruit both offenders and non-offenders for this study, all individuals with PAE had engaged in some type of criminal activity, ranging from shoplifting to physical assault. The difficulty in recruiting individuals with PAE that have had no involvement with the law speaks to the severity of the issue. Previous research has found that at least 60% of adults with FASD experience trouble with the law (Streissguth et al., 1997) and most offenders engage in a repeated pattern of criminality that leads to incarceration (Chudley et al., 2007). Thus, more research is needed to compare offenders and non-offenders with FASD with regards to protective factors from criminality.

This research did not employ quantitative measures to assess executive functioning, adaptive behaviour, or cognitive abilities. As a result, it is impossible to ascertain the extent to which deficits in these neurobehavioural domains contribute to delinquent behaviour in individuals with FASD. Although it is speculated that the difficulties with self-regulation and social behaviour discussed by participants are related to primary disabilities commonly found in FASD, it is impossible to verify the relationship with the reported deficits employing a qualitative methodology. More research is needed to determine the unique contribution of cognitive and environmental risk factors to the experience of criminality in individuals with FASD.

Another limitation of the study was the small number of adults with PAE who participated in this study. While the focus of the research was on the family experience, only two adults with PAE participated in the semi-structured interview. As a result, the majority of the perspectives presented herein are from the caregiver's point of view. A possible avenue for future qualitative research is to explore the experience of adults with FASD. Although attempts were made to include the voice of the individuals with PAE, it is important to consider that

conducting interviews with parent-child dyads may affect the information disclosed during the interview because participants may not be comfortable disclosing information in the presence of their parent or child. Families were given the choice of interviewing together or separately, and in both cases the family requested to participate in the study together.

### **Conclusion**

The present study explored families' perspectives on the factors that either increased or decreased the likelihood of delinquent behaviour in adults with PAE. Families reported that their children faced several risk factors for criminality, including difficulty with self-regulation, vulnerability to negative peer influences, susceptibility to substance abuse, and the experience of multiple transitions. Conversely, families found that structured environments, educational and occupational accommodations geared towards strengths, having access to supports, and increasing positive influences ameliorated life outcomes for individuals with PAE. The findings from this study highlight the importance of including the voice of families in research to inform policies aimed at preventing criminality and developing rehabilitative strategies that accommodate the developmental needs of individuals with PAE.

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## CHAPTER FOUR. CONCLUSION

The aim of this paper-based thesis was to explore the cognitive and environmental factors associated with criminality in adults with Fetal Alcohol Spectrum Disorder (FASD). The first paper identified some of the methodological challenges encountered while conducting a mixed methods study on adults with prenatal alcohol exposure (PAE). The second paper provided a qualitative exploration of families' perspectives on the risk and protective factors associated with criminality in individuals with PAE. A summary of the findings of each paper is provided in this chapter. A review of the findings within the theoretical framework is also provided. In addition, the strengths and limitations of the study are discussed. Finally, an overview of the practical applications of the research findings, as well as suggestions for future research are presented.

### **Summary of Findings**

The first article titled "Methodological Challenges in Conducting Research with Adults who have FASD" identified some of the limitations encountered in the present study, which sought to compare the experience of offenders and non-offenders with FASD. A mixed methods approach was employed to investigate the cognitive and environmental factors that increase or decrease criminality in adults with PAE. However, a myriad of practical and methodological limitations impacted the design and implementation of the research project. In accordance with some of the barriers delineated in extant research, some of the challenges encountered in the present study included difficulty accessing and recruiting individuals with FASD (Bohjanen, Humphrey, & Ryan, 2009; May et al., 2009), having a small sample size (Chasnoff, Wells, Telford, Schmidt, & Messer, 2010; Fagerlund et al., 2012), employing operational definitions that allow for comparisons across studies (Arenson et al., 2010; Pei, Job, Kully-Martens, &

Rasmussen, 2011), and choosing measures that are sensitive to the unique needs and vulnerabilities of individuals with FASD (Kully-Martens et al., 2012; Schonfeld, Paley, Frankel, & O'Connor, 2006b).

A significant methodological challenge encountered in this research project was related to the small sample size. Although attempts were made to find participants from various community agencies, all of the participants were recruited through online support groups for families of children with FASD. In order to increase the sample size, individuals with PAE strongly suspected of having FASD were included in the study. Despite the efforts made to obtain a sufficiently large sample size, only eight families participated in the qualitative interview. The sample consisted of biological, adoptive, and foster families who had at least one adult child with PAE (see Appendix B for a list of participant pseudonyms, family type and ages of children).

Another methodological issue found in research on FASD is related to the lack of consistency in the terminology employed. The operational definition of offender varies in existing literature, with some studies using this label to describe individuals who were charged or convicted of a crime (Clark et al., 2004; Lynch et al., 2003), while other studies define offenders as individuals who have been incarcerated (Burd et al., 2003). Because the focus of this study was criminal behaviour in adults with FASD, the term offender was used to refer to individuals who have engaged in criminal activity, including shoplifting, physical assault, and fraud. However, all of the adults with PAE in this study had engaged in some type of delinquent behaviour. As a result, the author was not able to compare and contrast the experience of offenders and non-offenders.

A final challenge that emerged was related to the selection and administration of appropriate psychometric measures. Individuals with FASD have primary disabilities such as impairments with memory (e.g., Green et al., 2009), language (e.g., Wyper & Rasmussen, 2011), and comprehension of abstract concepts (e.g., Malbin, 2004) that may interfere with their ability to complete standardized measures (Finlay & Lyons, 2001; Irvine, 2010). The Level of Service Inventory - Revised (LSI-R; Andrews & Bonta, 2001) is a structured interview that is administered individually to assess the risk of recidivism. Although this measure is commonly used in the general correctional population, participants in this study had difficulty remembering specific details (e.g., how many jobs they had in the past year) as well as information relating to specific time frames (e.g., how long they were in a specific relationship). The LSI-R endorses the use of collateral information; however, employment records, psychological assessment reports, and documentation from the criminal justice system were rarely available. Therefore, the LSI-R was administered in parent-child dyads so that caregivers could provide clarification or corroborative information when necessary. Collectively, the methodological challenges encountered in research on FASD highlight that there is a limited understanding of the multifaceted issues faced by individuals with PAE and their families and highlighted the need for further research.

The second article titled “‘He’s on the streets, and stealing and perpetuating the cycle... and I’m helpless’: Families’ perspectives on criminality in FASD” investigated the risk and protective factors associated with criminal behaviour in adults with PAE. Given the exploratory nature of this study, a qualitative approach was employed in order to reflect the voice of participants (Irvine, 2010). Following a basic interpretive approach (Merriam, 2002) which seeks to understand the meaning individuals ascribe to their experiences, semi-structured interviews

were conducted with eight families of adult children with PAE. A summary of the superordinate themes and constituent subthemes presented in Chapter Three are provided in Appendix C. With regard to the factors that contributed to criminality, four superordinate themes were identified: behavioural and emotional self-regulation, peer group, substance use, and multiple transitions.

Families named their child's difficulty with self-regulation and inhibitory control as important contributors to criminality. All eight parents expressed that their child's involvement with the criminal justice system was associated with aggressive or impulsive behaviour. Parents also indicated that their children displayed lifelong social deficits that rendered them vulnerable to negative peer influences. In line with previous research findings, individuals with PAE in the present study rarely engaged in criminal activity alone (Brown et al., 2012). Caregivers reported that their children lacked the social skills required to develop and maintain positive interpersonal relationships. In order to satisfy their desire to belong to a social group, individuals with PAE were often drawn to friends who engaged in anti-social behaviour, such as truancy, substance use, and criminality. Seven parents reported that their children's criminal activity occurred while under the influence of alcohol or drugs and that substance use typically occurred as a result of negative influences from friends. Finally, families spoke of the adverse effect of having multiple transitions in the home environment. Parents stated that their children's impulsive tendency to abscond led to several successive moves from one household to another. Six parents in this study indicated that without structure and supervision, their children ultimately faced legal issues.

With regard to protective factors that decreased the likelihood of criminality, the importance of structure was a predominant superordinate theme discussed by all parents in this study. Families indicated that their children's criminal behaviour often occurred when there was a lack of structure and supervision. Another superordinate theme that emerged was the

importance of education and employment. Five parents in this study reported that educational programs and employment offered a structured venue in which positive social connections could be fostered. However, parents emphasized the need to tailor academic programs and employment to the unique strengths and vulnerabilities of their children.

Families also spoke of the importance of having financial, social, and emotional supports. However, parents also spoke of the lack of FASD-specific supports and the need to incur the financial burden of accessing the available supports due to the dearth of monetary assistance. In addition to individual support, parents also discussed the importance of supports for the family, such as parent support groups. A final theme pertaining to protective factors against criminality was the role of positive influences. Parents noted that having a strong social support system consisting of friends, family members, neighbours, community supports, and advocates helped instil hope and resilience in their children. Furthermore, families indicated that having strong role models helped their adult children believe they could lead happy, productive lives. However, parents reported that the lack of knowledge on FASD made it difficult to find role models that understood their child's disability and were consequently able to provide appropriate support and encouragement. Thus, many parents took on the role of advocates for their children and were therefore a positive influence by helping their children access the services they needed to prevent the development or exacerbation of secondary disabilities, such as criminality.

In summary, the findings presented herein have provided the following answers to the research questions:

- 1) Some of the methodological challenges relating to conducting research on adults with PAE include recruitment, finding participants with a diagnosis, establishing

- operational definitions that allow for comparisons across studies, and finding measures that are sensitive to the primary and secondary disabilities.
- 2) Criminality in adults with PAE is associated with a poor fit between the individual's capabilities (e.g., cognitive deficits) and the environmental demands (e.g., expectations that they meet societal standards such as sitting quietly and attentively in a classroom all day). Cognitive risk factors for criminality identified by parents included difficulties with inhibitory control, emotional dysregulation, and impairments in social skills. However, environmental factors such as structure and supervision, education and employment, positive influences, and having access to supports and services helped mitigate the effects of criminality.
  - 3) Parents reported that difficulties with self-regulation and social skills, coupled with substance use and multiple transitions, were contributing factors to criminality. Although each risk factor was identified as a distinct superordinate theme, a common denominator that emerged in the qualitative interviews was that primary disabilities interfered with the ability to cope with life stressors. Without the appropriate environmental accommodations, secondary disabilities such as criminality developed over time.
  - 4) Protective factors that decrease the likelihood of criminality in adults with PAE included structure and supervision, education and employment tailored to the unique strengths and vulnerabilities of the individual, having positive influences, and having emotional, social, and financial support.

## **Towards a Theoretical Model: Integrating Research and Theory**

The majority of research conducted on FASD draws on general theoretical models; however, these theoretical frameworks are based on typically-developing individuals without brain dysfunction. While such models may be useful in guiding exploratory studies, there is a need for theory-driven research that is FASD-specific and that takes neurodevelopmental factors into account (Kodituwakku, 2010; Olson et al., 1998; Rasmussen, 2005). The preponderant theoretical model used in current research proposes that maladaptive behaviours in FASD are caused by underlying neurobehavioural deficits (Brown et al., 2012; Fast & Conry, 2009; Malbin et al., 2010). Malbin and colleagues (2010) proposed a neurobehavioural model of criminality in which criminal behaviours occur as a chronic dissonance between an individual's capabilities and the environmental demands placed upon them. It is hypothesized that cognitive deficits, particularly impairments in executive function, interfere with the ability to self-regulate, grasp social cues, control impulsive behaviour, anticipate consequences, and learn from mistakes or the mistakes of others (Coggins et al., 2007; Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995). Furthermore, environmental demands such as multiple transitions and lack of structure may exceed the individual's capabilities to adapt to situations and consequently, individuals with FASD are more likely to display maladaptive behaviour that may lead to delinquent behaviour (Page, 2002; Fast & Conry, 2009; Malbin et al., 2010).

The findings from the present study are consistent with the neurobehavioural model. All of the families discussed how primary disabilities were an underlying cause of criminal behaviour. Seven parents reported that their child's involvement with the criminal justice system stemmed from emotional dysregulation that led to physical assault or destruction of property. In other cases, parents attributed their child's offending behaviour to impulsivity and difficulty

understanding consequences. However, parents reported that once they understood that their child's behaviour was caused by CNS dysfunction and was not willful, they were better equipped to meet their child's needs. As outlined in the neurobehavioural model, the most effective interventions involve modifications to the individual's environment.

While there is compelling empirical support for the role of neurobehavioural deficits in the development of criminality in adults with FASD, it is also important to consider the social and environmental risk factors (Coggins et al., 2007; Lynch et al., 2003). The Risk-Need-Responsivity (RNR) model delineates the "central eight" risk/need factors that drive criminal behaviour in the general correctional population (Andrews & Bonta, 2010). The risk and need factors can be categorized along different dimensions, including personal characteristics (i.e., history of criminality, pro-criminal attitudes, impulsivity, aggression, and substance use), familial circumstances (i.e., strained relationship with family members and lack of stability in the home environment), and social environment (i.e., academic difficulties, unemployment, and negative peer influences). To address the need for more theory-driven research, an integration of the research findings within each level of the RNR model will be presented.

**Individual characteristics.** As expected, individuals with FASD have some vulnerabilities that predispose them to criminality, such as a history of antisocial behaviour (Schonfeld et al., 2006a; Streissguth et al., 2004), antisocial personality patterns (Brown et al., 2012), and antisocial associates (Fast & Conry, 2009; Kully-Martens et al., 2012). In the context of the RNR model, the term antisocial refers to behaviour that is inconsistent with societal expectations (Andrews & Bonta, 2010). However, deficits in adaptive function indicate by definition that individuals fail to meet standards of social conduct and independent living (American Psychiatric Association, 2013). Furthermore, deficits in executive functioning in

domains such as response inhibition (e.g., Connor et al., 2000), attention (e.g., Green et al., 2009), and working memory (e.g., Rasmussen, 2005) may lead to maladaptive behaviour and impaired social functioning (Kully-Martens et al., 2012; Kully-Martens et al., 2013). The present study concluded that individuals with FASD are likely to meet the criteria for antisocial traits, including a history of aggressive and impulsive behaviour, violation of rules and probation conditions, and associating with peers that favour antisocial behaviour.

Where offenders with FASD might differ from typically-developing offenders is in terms of antisocial cognitions, which implies that individuals hold beliefs and attitudes that are in favour of criminality and intentionally engage in illegal activities. There is a wealth of research suggesting that individuals with FASD may not have the cognitive ability to meet legal standards for criminal intent (Brown et al., 2010; Fast & Conry, 2009; Moore & Green, 2004; Roach & Bailey, 2009). From a psycholegal perspective, deliberate criminal behaviour involves decision-making in complex, social situations (McLachlan et al., 2013; Kully-Martens et al., 2013). The self-regulation involved in criminality requires individuals to be aware of cues from the social context, rely on cognitive and emotional processes to make decisions, and inhibit behaviour that is in violation of social norms (Brown et al., 2012; Kully-Martens et al., 2013). However, individuals with FASD show marked deficits in these self-regulatory abilities (Connor et al., 2000; Kodituwakku et al., 2001; Kully-Martens et al., 2012). While criminal behaviour is often attributed to defiance, conduct problems, antisocial attitudes, and lack of motivation, it may be the case that deficits in executive functioning, adaptive behaviour, and social skills may be a more accurate explanation for criminality in FASD (Brown et al., 2012; Malbin et al., 2010). The hypothesized role of neurobehavioural deficits in criminality is consistent with findings from this study, in which parents attributed their child's delinquent behaviour to impairments caused by

central nervous system dysfunction. Thus, at the individual level, it is likely that offenders with FASD are at greater risk for criminality because of the primary disabilities caused by PAE.

**Family characteristics.** Previous research has highlighted the impact of the caregiving environment on the life outcome of individuals with FASD (Koponen et al., 2009; Streissguth et al., 2004). Many children with FASD experience multiple transitions from household to another (Fagerlund et al., 2011; Sarkola, Kahila, Gissler, & Halmesmäki, 2007). In this research project, seven parents characterized the home environment as chaotic and unpredictable. It is important to note the bi-directional relationship between self-regulation and the home environment. On the one hand, parents in this study expressed that their children's inability to regulate emotions and behaviour created an unstable environment. Challenging behaviours have also been linked to increased parenting stress in families of children with FASD (Jirikowic et al., 2012; Paley et al., 2006; Paley et al., 2005; Watson et al., 2013a), which may also have an impact on the home environment (Paley et al., 2005). On the other hand, structure and consistency in the home environment is necessary to develop self-regulatory skills (Brown et al., 2012). Consequently, challenging behaviours may be caused in part by difficulty with self-regulatory abilities; however, these behaviours may have an effect on the environment and therefore interfere with the development of emotional and behavioural self-regulation. Thus, familial factors can act as either risk or protective factors depending on the level of stability that exists within the home environment.

**Social environment.** Another cogent predictor of criminality is the social environment of the individual (Andrews & Bonta, 2010). Families in this study spoke of the social isolation experienced by their children with PAE. In particular, parents expressed that their children had difficulty forming and maintaining positive friendships with peers. When they did make friends,

individuals with PAE had a tendency to become involved with peers that engaged in substance use, truancy, and criminality. As discussed previously, primary disabilities are believed to be underlying causes of the social skills deficits in FASD (Kully-Martens et al., 2012). Conversely, parents in this study stressed that positive social influences helped instil a sense of hope in their children. Five families reported that education and employment were important factors in preventing criminality in adults with PAE because they provided structured settings in which positive social connections can be developed. Streissguth and colleagues (1997) found that the occurrence of criminality doubled when individuals with FASD had disrupted school experiences. While the importance of education and employment has been established, high rates of unemployment (at least 79%) have been found in adults with FASD (Spohr et al., 2007; Streissguth et al., 1997). Even with educational and vocational training programs, 87% of adults with FASD were unable to maintain regular employment (Spohr et al., 2007). The findings from this study and extant literature highlight the need for environmental modifications to mitigate the effects of secondary disabilities in adults with FASD.

**Responsivity.** The findings from this study show that offenders with FASD are likely to have one or more risk factors at the individual, familial, or social level. Furthermore, it appears that primary disabilities such as impulsivity, aggression, and social impairments are underlying influences that drive criminal behaviour in adults with PAE. As a result, they are considered to be “static” risk factors that are not amenable to change through traditional rehabilitative efforts. The findings from this study are reflective of the requirement for more appropriate treatment for offenders with FASD. Rather than focusing on the risks and needs of offenders with FASD, it may be more effective to address the issue at the responsivity level, which involves using empirically supported interventions that are sensitive to the strengths and needs of the individual.

There is strong support in the clinical and scientific literature that more appropriate treatments are necessary for offenders with FASD (Boland et al., 2002; Burd et al., 2010; Fast & Conry, 2009; McLachlan et al., 2013).

### **Criminality in FASD: A lifespan issue**

The findings from this study supported previous research, which suggests that individuals with FASD are overrepresented in the criminal justice system. It has been found that 60% of individuals with FASD will experience trouble with the law (Streissguth et al., 1997) and that the first offense typically occurs around the age of 12.8 years (Streissguth et al., 2004). Furthermore, a systematic review of the prevalence rate of FASD in the Canadian correctional system found that compared to the general population, youth with FASD are 19 more likely to be incarcerated (Popova et al., 2011). Despite the high likelihood of facing legal problems, another Canadian study showed that 23.3% of youth remanded to a forensic or psychological assessment met the criteria for FASD. However, only 1% of the youth assessed had a diagnosis prior to the mandatory assessment (Fast et al., 1999). Although individuals with FASD are at an increased risk for criminality, only a small proportion of offenders with PAE are diagnosed prior to their involvement in the criminal justice system. In the present study, all adults who were exposed to alcohol prenatally engaged in criminal activity and were therefore considered to be offenders.

Equally concerning is the fact that while individuals experience trouble with law at a young age, criminality continues to be a challenge for adults with FASD (Streissguth et al., 1997; Chudley et al., 2007). A possible explanation for the lifelong legal issues is that the management of FASD is primarily occurring in the criminal justice system. Individuals with FASD may not receive a formal diagnosis and are consequently unable to access the necessary services and

supports to prevent the development of secondary disabilities. The majority of families in this study discussed the difficulties they encountered in trying to access diagnostic and treatment services for their children. Of the 10 adult children in the study, only 60% had received a formal diagnosis. Furthermore, of the 6 adults with a diagnosis, only four participants had been diagnosed as children. Five parents spoke of the importance of having a diagnosis to better understand their children's challenging behaviour. Sadie, an adoptive mother to a son and a daughter with PAE, explained how understanding her children's disability helped her reframe the challenging behaviours they displayed:

Well once we understood FASD we could understand, hey they're not choosing this behaviour, you know? This is what is happening, what they are doing is resulting from FASD. It was certainly helpful to know that and that you can't change their brain.

Similarly, Audrey, an adoptive mother to a 38-year-old daughter with PAE, stated: "I haven't been angry with my daughter since I've understood what FASD was. I used to be mad at her all the time. I wanted her to smarten up, quit ruining her life, quit embarrassing us." However, four parents expressed regret that their understanding of FASD occurred once their children were too old to benefit from early intervention. As Caroline, an adoptive mother to a 22-year-old son with PAE reported, "It was too little, too late." The narrative of parents in this study emphasized the importance of obtaining a diagnosis in order to prevent secondary disabilities, such as criminality. Consequently, more diagnostic clinics are needed, particularly in rural and isolated communities (Legge, Roberts, & Butler, 2000; McFarlane & Rajani, 2007).

Another possible explanation for the high rate of recidivism in adults with PAE is that current rehabilitative efforts, which are based on a cognitive approach, are less effective for

individuals with FASD (Boland, Burrill, Duwyn, & Karp, 1998; Brown et al., 2012; Page, 2002). While the need for more specialized services has been documented in previous literature (Brintnell, Bailey, Sawhney, & Keftin, 2010; Chudley et al., 2007; Cox, Clairmont, & Cox, 2008; Fast & Conry, 2009), there is a paucity of research to guide evidence-based treatments for offenders with FASD. The available research suggests that treatment should focus on implementing environmental modifications and building on the strengths of the individual:

The logic of this [neurobehavioural] model as applied to FASD is as follows: Since brain damage is a physical disability that has behavioral symptoms, it follows that people with FASD would benefit from interventions based on the same principle as those that are provided for people with other, more obvious physical disabilities, namely environmental accommodations. Just as wheelchairs and ramps provide safety and accessibility for those with paralysis, people with FASD also require accommodations. (Malbin, 2004, p. 57)

According to the findings from this study, environmental accommodations should target the degree of structure and supervision in the home environment, facilitating access to educational programs and employment, improving emotional, social and financial supports for individuals with FASD and their families, as well as building a strong network of positive influences. In order to meet this demand, more services are needed within the health care and educational sectors in order to employ a preventative approach to criminality in FASD.

### **Areas for Consideration**

A limitation of this study was the small sample size. Although the sample size was sufficiently large for the qualitative component, the quantitative measures could not be included in the results. As a result, it is not possible to ascertain to what extent deficits in cognitive

abilities, executive functioning, and adaptive behaviour are involved in criminality in adults with FASD. Parents in this study described impairments in self-regulatory processes; however, without direct measures of cognitive factors it is unknown if these impairments fall within the clinical range. Given that self-report may be influenced by variables such as the relationship of the informant to the child or the context in which the behaviour is observed (Schonfeld et al., 2006b), researchers advocate for the use of measures that assess cognitive domains directly (Kully-Martens et al., 2012).

Another limitation of the study was that the sample consisted only of mothers. Although the term “parents” and “caregivers” were widely used in this thesis to describe participants, it is important to note that the voice of male family members was not represented. While fathers and grand-fathers were invited to participate in the research project, the sample did not include any patriarch family members. It is possible that fathers may have a different perspective than mothers, and it is therefore essential to keep sample characteristics in mind when interpreting the results.

A third limitation of the study is the use of a clinical sample. All participants were recruited from online parent support groups from across Ontario. Consequently, it is likely that participants shared similar characteristics. For example, all parents in this study reported that their children exhibited challenging behaviours. It may be the case that parents sought emotional support from parent groups because of the severity of their child’s behaviour. One of the risks of using a clinical sample is that participants may have more deficits than individuals with PAE who did not require access to services, thereby limiting the generalizability of the findings. Similarly, the generalizability of the results may be limited by the fact that not all of the adults with PAE in this sample had received a diagnosis of FASD. Thus, the findings from this study

may not be representative of the experience of all adults with FASD. Furthermore, it remains unclear whether obtaining a diagnosis impacts the experience of families by improving access to treatment.

Lastly, this study does not allow for a comparison of offenders and non-offenders with FASD. Despite efforts to recruit individuals with and without a history of criminality, all adults with PAE had engaged in at least one act of criminality. Parents spoke of protective factors that helped improve the life outcome for individuals with FASD. However, it is important to keep in mind that the findings from this study do not speak to the protective factors that help prevent criminality in adults with FASD.

### **Strengths of the Study**

This study had some notable strengths. First, employing a qualitative approach allowed for the inclusion of families' voices and perspectives. There is a need for more qualitative research on developmental disabilities (Esdaile & Greenwood, 1995; Watson et al., 2011), particularly when studying FASD (Jirikowic et al., 2008; Olson et al., 2009; Watson et al., 2013a; Watson et al., 2013b). Unlike quantitative measures that offer finite responses, qualitative research provides an opportunity to consider variables that might otherwise be overlooked by researchers. Based on their lived experiences, families have important insight on the unique challenges and needs of individuals with FASD. Accordingly, parents can provide valuable information to guide exploratory research as well as the development of policies. Including families in research is mutually beneficial for participants. Parents who took part in this study thanked the author for providing them a platform from which they could share their story. In

particular, parents expressed a desire to help other families by articulating their hardships and successes.

In line with the essential characteristics of qualitative research, this study followed recommended guidelines to ensure the reliability and validity of findings. Researchers have emphasized the need to promote trustworthiness, which is defined as the extent to which the study measures the intended phenomenon (Merriam, 2002; Shenton, 2004). The trustworthiness of interpretive research is established through rigorous data collection techniques, including prolonged engagement, member checks, and progressive subjectivity (Merriam, 2002).

Prolonged engagement involves providing sufficient time during data collection to establish trust and adequately capture the meaning participants ascribe to their experiences (Lincoln & Guba, 1985; Shenton, 2004). Although there is no set standard for the length of interviews, researchers must afford enough time to reach a saturation of information, such that new themes are no longer emerging and there is repetition of material (Merriam, 2002). The length of the semi-structured interviews in the present study varied from one participant to another. An interview was considered to be complete once themes were well-developed and there were no outstanding questions to be answered by participants.

The credibility of the study was also established through member check, whereby parents were given the opportunity to verify that their experiences were being accurately captured by the researcher (Merriam, 2002). The author provided a summary of the information shared by participants at the conclusion of each interview, and parents were asked to confirm the exactitude of data. In order to ensure the accurate representation of the voice of participants, the interviews

were digitally recorded and transcribed verbatim. Following data analysis, a peer review of the superordinate themes and subthemes was conducted by the author's supervisor.

Progressive subjectivity is a technique used to identify and monitor perspectives and assumptions held by the researcher that may influence the interpretations contained in the research (Shenton, 2004). To increase the credibility of the present study, a reflexivity section was included in the first chapter, delineating the personal and professional that influenced the lens through which this research project was conducted. The continuous efforts to adhere to the principles of trustworthiness are a strong point of this research project.

Another strength of this study was that it examined both risk and protective factors. The bulk of research has sought to identify the influences that lead to criminality in adults with FASD; however, few studies have considered the factors that can prevent or mitigate the effects of secondary disabilities. Previous research has found that a stable, nurturing home environment consisting of supportive parenting as well as structure may lead to more positive life outcomes for individuals with FASD (Olson, O'Connor, & Fitzgerald, 2001). Nevertheless, there is a dearth of knowledge on the specific protective factors for criminality in FASD. The lack of research is surprising given that many professionals have emphasized the need to develop interventions that consider the strengths of the individual as well as some of the protective factors that may help decrease the occurrence of secondary disabilities (Malbin et al., 2010; Olson et al., 2009; Page 2002). The present study offers some areas of focus for future policies or interventions, including social functioning, education, employment, and supports for families and individuals.

## **Recommendations for Future Research**

In considering the aforementioned strengths and limitations, it is evident that there is a need for further research on the risk and protective factors associated with criminality in FASD. Collaborations between researchers and community agencies are required to increase sample size and address issues with sample characteristics, including the need for non-clinical samples and participants with less severe deficits. Larger sample sizes allow for statistical analyses that detect small effects (D'Onofrio et al., 2007). Furthermore, the generalizability of research findings can be improved by recruiting participants from a variety of settings.

Similarly, collaborative efforts between researchers can improve future research by increasing the consistency in the terminology used in diagnostic labels and operational definitions (Arenson et al., 2010). By employing more standardized nomenclature, it is possible to make comparisons across studies. Given that small sample sizes are a predominant problem in research on FASD, the synthesis of findings from various studies may help improve the understanding of criminality in adults with FASD.

Moreover, there is a need for more qualitative research that examines the meaning ascribed by individuals with FASD and their families to their lived experiences. Rather than relying on a single methodological design, the use of mixed methods strengthens research by triangulating the results from quantitative and qualitative approaches (Erzerberger & Kelle, 2003). Research on criminality in FASD is challenging because of the complex interaction between primary disabilities and postnatal environmental factors. Mixed methods research allows for the simultaneous consideration of cognitive and environmental factors. While this study attempted to employ a mixed methods design, a myriad of methodological challenges

impeded the use of the quantitative portion. A possible avenue for future research is to investigate the risk and protective factors associated with criminality in FASD in a larger sample using a mixed methods approach.

Finally, future research should seek to compare the experience of offenders and non-offenders with FASD to gain a better understanding of the protective factors that help prevent criminality in adults with FASD. The focus of previous research has been primarily the risk factors, and there is a need for more theory-driven research on the protective factors that lead to more positive life outcomes (Olson et al., 1998; Rasmussen, 2005). In particular, the LSI-R is based on the RNR model and as such is rooted in theory and empirical evidence. More research using the LSI-R would help identify areas that increase or decrease the likelihood of criminality in FASD.

### **Recommendations for Clinical Practice**

In addition to providing future directions for research, the findings from this study can help inform clinical practice and policies. There was overwhelming consensus among families that the management of FASD required a team consisting of family members, neighbours, friends, health professionals, child and youth workers or education assistants, teachers, and parole officers. Nevertheless, all of the parents in the study discussed the lack of supports for individuals with FASD. One of the concerns raised by parents was the lack of knowledge on FASD by professionals. Parents reported that medical professionals had limited understanding of FASD, particularly when the characteristic facial features were absent. Consequently, families were not able to obtain a diagnosis for their children. As previously suggested, it is possible that not having a formal diagnosis prevents individuals with PAE from accessing services and may

subsequently increase the risk of criminality. Families stressed that there is an imperative need for more education on FASD for professionals of all disciplines.

Even when a diagnosis was given, families faced a barrier in accessing services. Parents indicated that they had to advocate tirelessly for their children to obtain the necessary supports such as educational assistants, tutors, and caregivers. One mother reported that her adoptive child was only receiving help from an educational assistant because a student with autism in his classroom required this support. When discussing the need for more services and supports, it is important to specify that parents are looking for social supports that are specific to their child's needs. Another concern raised by parents was the need for financial support to access the available services. Parents reported that they were often financially responsible for any services accessed. Therefore, it is necessary to consider that clinical services need to be sensitive to the strengths and vulnerabilities of the individual as well as the financial means of the family. More government funded or subsidized services are needed to provide the support families need to improve the outcome for their children.

This study also highlighted the positive impact of focusing on building the strengths of adults with PAE. Families noted that including positive influences and building hope served as important protective factors against criminality. Treatment plans should therefore focus on environmental accommodations as well increasing the strengths and resilience of individuals with FASD (Green, 2007; Malbin et al., 2010; Page, 2002).

There is also a need for family-centred supports for families of children with FASD. There are convergent results suggesting that the family system and the caregiving environment play a significant role in the development of individuals with FASD. Given that parents are often

lifelong caregivers for their children (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008), they also require supports including behaviour management techniques, emotional support, and respite. By strengthening the family, interventions are improving the overall outcome for individuals with FASD (Olson et al., 2009).

## **Conclusion**

In conclusion, this study explored the cognitive and environmental factors associated with criminality in FASD. According to families, the life outcome of individuals with PAE is predicated on the following risk and protective factors: 1) the presence of cognitive impairments (e.g., deficits in self-regulation and social skills), 2) the environmental demands placed on the individual, and 3) the availability of supports and positive influences. Understanding the experience of adults with PAE and their families assists in the development of programs aimed at preventing or reducing criminality in FASD. In particular, this study highlighted the need for more social and financial supports that are FASD-specific. Currently, a large proportion of individuals with PAE do not receive a diagnosis or treatment until they are involved with the criminal justice system. As a result, there is a need to shift the management of FASD from the judicial sector to the health care and educational systems.

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## Appendix A.

## Interview Guide for Parents

1. Tell me about your son/daughter. What is he/she like?
2. What is it like being a parent to your son/daughter?
3. When did you first suspect that your son/daughter had FASD?
4. How old was your son/daughter when he/she received the diagnosis of FASD?
5. What kind of supports or services for FASD has your son/daughter received?
6. If you think back to your son/daughter's childhood and adolescence, how would you describe the home environment?
7. Please describe your child's current living arrangement.
8. Before the age of 18, in how many different households did your son/daughter live?
9. What were their living arrangements like in the past?
10. Was there a time in your son/daughter's life when you would say they did not have their basic needs met? (Follow-up: If so, at what ages?)
11. What were the challenges you faced during that time?
12. Can you tell me about the most positive time during your son/daughter's life?
13. At which ages would you describe your son/daughter's living situation as stable and nurturing?
14. Can you describe some of the challenging behaviours your son/daughter exhibited before the age of 18?
15. Can you describe any strategies or supports you used to help you deal with these behaviours?
16. What did you find helpful in dealing with the challenging behaviours?
17. How would you describe your son/daughter's relationship with his/her friends?
18. Has your son/daughter ever been the victim of physical abuse, sexual abuse, or domestic violence?
19. Can you tell me about your child's alcohol or drug use? (Follow-up: Can you describe what that experience was like for you and for your child? Can you tell me at which ages he/she used alcohol and/or drugs?)

20. How would you characterize your child's relationship with the law? (Prompt: problems with police, accused of a crime, convicted of a crime)

If there is involvement with the law:

- a. What was the most difficult part of that experience?
- b. What was the most helpful during that experience?
- c. What factors do you think contributed to your son/daughter's involvement with the law?

If there is no involvement with the law, why do you think your son/daughter did not experience any trouble with the law?

21. If you could have any services or supports, which services would you have wanted?
22. How is having access to services meaningful to you? (Prompt: Why do you think having access to services is important?)
23. Do you think that there is something that could have changed the outcome for your son/daughter's life, either in a positive or negative way? (Prompt: Is there anything that could have improved or worsened the outcome of your son/daughter's life?)

## Appendix B.

## Participant Pseudonyms by Family, Including Age of Adult Child(ren)

Participant Pseudonym		Family Type	Age of adult child
Parent	Adult child		
Lauren	Isabella	Biological	38
Sadie	Maria	Adoptive	33
	Dawson	Adoptive	35
Emma	Jordan	Custodial grandmother	22
Caroline	Noah	Adoptive	22
Kate	Cody	Adoptive	32
Tara	Gavin	Adoptive	27
Leah	Logan	(Biological)	42
	Chloe	Custodial grandmother*	19
Audrey	Serena	Adoptive	38

\* This participant's primary caregiving role was as a custodial grandmother and considered this to be her family type.

## Appendix C.

Summary of the superordinate themes and constituent subthemes presented in Chapter Three

<b>Superordinate theme</b>	<b>Sub-themes</b>	<b>Example of illustrative quotation</b>
“It felt like a tornado was in the house”: Emotional and behavioural self-regulation	Aggression	Threatened to kill us... we had to call the police sometimes because he wouldn't, he wouldn't calm down. – <i>Caroline</i>
	Impulsive behaviour	No I guess, it's just those behaviours, impulsive behaviours. Not thinking of consequences. Just sort of getting involved in the moment, you know. What's happening or just doing it and, just not thinking ahead. – <i>Sadie</i>
“Needed to belong, needed to be accepted”: Peer group	Lack of friends	And a lot of the kids that succeed are like that. They're very, very, very isolated. Because they're trying to stay away from the dangerous places. But they don't have anywhere else to go. Nobody wants them around. – <i>Kate</i>
	Negative influences	And she began associating with whoever would give her any attention... [W]ell her best friends are six boys who are all in trouble. Like they were in trouble with the law, even. So from then on it went downhill. – <i>Audrey</i>
“It's a battle every day”: Substance use		And he's done every kind of drug there is. He's told a worker he's murdered someone for his drugs – <i>Leah</i>
“It was just a continuous chaos”: Multiple transitions		And just went from friend to friend, house to house. She was in foster care. Because you weren't allowed just on the street so obviously, and then I would guess I don't think I'm exaggerating if I say she lived in 20 different places between the ages 13 and 20. – <i>Audrey</i>

“His behaviour is not going to change until you change his environment”: Structure and supervision

But in the long run like we’re sitting here today saying all the risks I didn’t let him take. The fact that he hasn’t had a criminal record is because he was, we contained his environment. – *Tara*

“If he had been able to get an education then I think he’d be able to be a functioning member of society”: Employment and education

He’s always looking for work because the biggest, biggest thing that we would notice is that filling his spare time is essential, that he cannot have spare time. – *Kate*

“They really wanted him to succeed in this endeavor and not end up in jail”: Supports

Supports for individuals with PAE

They really wanted him to be safe. It was nice, it was a miracle. – *Kate*

Supports for the family

The FASD parents support group. And so you know you can talk about your issues and problems with you kids there so that helps because you know you’re not the only one. – *Sadie*

“I just surrounded her by what I consider really positive forces”: Positive influences

Positive peer group

He’s got friends. He’s very social kid. Um, and, is, uh, I think confident of himself, about his own skills. – *Emma*

Parents as advocates for their children

You know so, I’ve had to be his advocate and in many, many ways. Physically and mentally. – *Tara*