

“If we get beyond the stereotype”: Professionals’ experiences attending to FASD, social supports and stigma in Newfoundland and Labrador.

by

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Abstract

Fetal alcohol spectrum disorder (FASD) is a complex and lifelong neurodevelopmental disorder that affects individuals' need for support in daily living. A multitude of factors, such as adverse early life experiences may impact the need and type of support(s) required. In this thesis, I explore forms of support, stigma, and professionals' experiences working in the healthcare and justice fields with individuals diagnosed with FASD in Newfoundland and Labrador (NL).

Drawing on case reports of an FASD specialist, three case studies are presented that focus on the impact of FASD diagnosis, and forms of support and intervention throughout these individuals' lives. These are complemented by seven semi-structured interviews with justice and health professionals. Findings illustrate issues of visibility of FASD and stigma, the need for life-long support, and for increased early formal supports and interventions. I discuss implications for justice-involved individuals with FASD and the necessity for long-term supportive interventions from health and justice systems.

Keywords: Fetal alcohol spectrum disorder; health; justice system; stigma; formal support; informal support; supportive interventions

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CHAPTER 1

INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is a neurodevelopmental disorder caused by prenatal exposure to alcohol. Individuals diagnosed with FASD encounter various challenges in their daily lives from challenges at home and school to difficulty following broader social norms. The role of social supports in mitigating (or contributing to) these experiences is complex. A multitude of factors, such as adverse early life experiences, may also increase an individual with FASD's susceptibility to encounters with the police and involvement with the criminal justice system. The objective of my master's research is to enhance understanding of the role of social supports in shaping the experiences (e.g., periods of incarceration or hospitalization, periods of stability in the community, employment, social relationships) of people diagnosed with FASD in Newfoundland and Labrador (NL). Using developmental theory, which acknowledges the importance of various experiences affecting individuals throughout their development, I pursued this research through the examination of summary case reports authored by an FASD specialist in NL. Additionally, interviews with seven professionals in the justice and health fields were conducted to provide a comprehensive view of issues that persons involved in the justice system with FASD face in the province. The three case studies, based on individual summary case reports, focus on a number of early life factors including circumstances about FASD diagnosis and various forms of supports these individuals have experienced, along with circumstances of their criminal involvement. The interviews provided insight into the firsthand experiences of professionals working with individuals with FASD in the criminal justice and healthcare systems and assess strengths and challenges as well as existing service gaps.

My main objective in this thesis was to explore the experiences of professionals working with individuals who have been diagnosed with FASD who are justice involved and to examine the role of various forms of formal and informal supports that may have impacted or supported these individuals. In addition, I identify some forms of supportive interventions specific to home and living environments, as well as related supports as a means to strengthen efforts toward intervention and prevention of justice involvement in NL.

My thesis consists of six chapters. Following this introduction, in chapter 2 I provide a review of the literature on FASD and its complex, lifelong impacts in relation to individuals who are justice-involved; this is followed by a discussion of the scope of FASD work to date in NL. In the same chapter, I discuss Goffman's theory of stigma, in addition to the developmental theoretical framework as it relates to the study of antisocial behaviour and how it serves as an appropriate framework for the present research. Chapter 3 is where I outline the methodological approaches I used in this research and provide information about the data collection process. Further, I position myself as a researcher in a field in which I have both professional and personal experiences with FASD. In chapter 4, I present my research findings, organized first by case studies and then interviews and, in chapter 5, I present my findings in relation to pertinent literature and how the results can be understood within a proposed developmental pathway. I also discuss the implications of my findings for professionals and justice-involved individuals with FASD in the province. In chapter 6, I return to my research question and conclude my thesis by reviewing recommendations stemming from the findings and situating this research to further professionals' understanding of FASD, support, and stigma within NL.

CHAPTER 2

LITERATURE REVIEW & THEORETICAL APPROACHES

What is FASD?

Fetal alcohol spectrum disorder (FASD) is a diagnostic term referring to a spectrum of disorders and subsequent permanent disabilities caused by prenatal exposure to alcohol during pregnancy that persist throughout life (Chudley et al., 2005; Cook et al., 2016). The permanent and irreversible nature of this disability can result in a range of difficulties that manifest differently across individuals; these are often summarized as ALARM: poor adaptive functioning; language deficits; attention problems; deficiencies in reasoning skills, and poor memory (Fast & Conry, 2004, 2009). Characteristics of this disorder can be expressed through lifelong physical, neurological, and behavioural issues and may be accompanied by growth deficiencies, central nervous system dysfunction and, occasionally, facial feature anomalies (Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, 2003; Fast & Conry, 2009).

FASD may also contribute to the development of secondary challenges,¹ which may include difficulties in school, negative peer influences, substance abuse, mental health issues, and challenges with independent living and learning, and following social cues (Fast & Conry, 2009; Streissguth, Barr, Kogan & Bookstein, 1997). When left unaddressed, the combination with low executive functioning, impulsivity, and difficulty understanding cause and effect may result in involvement with the criminal justice system for an individual with FASD (Burd, Fast, Conry, & Williams, 2010; Fast & Conry, 2009). If involved with the justice system, individuals

¹ Secondary challenges have commonly been referred to as secondary disabilities. However, there has been a shift away from this language as a result of the challenges of delineating primary from secondary disabilities (CanFASD, 2018).

with FASD may experience further struggles due to their poor memory and recall, and difficulty learning from previous actions/experiences.

Researchers suggest there are numerous risk factors tied to the consumption of alcohol during pregnancy on the developing fetus, which are intensified by higher maternal age, paternal drinking, and drug use during pregnancy, which may be exacerbated by education level, socioeconomic status, custody changes involving other children, and paternal drinking (e.g., Sood et al., 2001). Other research has shown that limited access to prenatal and postnatal care, poor nutrition, and difficult living environment (as a result of violence, stress or abuse) are additional risk factors for the development of FASD (Bingol et al., 1987); these factors can arise regardless of educational, economic, and racial backgrounds (Astley et al., 2000).

Despite this broad range of challenges, individuals with FASD often present with wide variation in their IQ levels (Streissguth et al., 1996), which can result in the disability often being less visible or undetectable, and in effect, missed opportunities for appropriate interventions and supports. Adding to the complexity of identifying FASD is the presence of comorbid health and mental health issues, which can complicate the diagnosis and intervention processes. In a systematic review, Popova et al. (2016) found numerous co-occurring conditions amongst individuals with a diagnosis of FASD. The comorbid conditions varied from congenital malformations, deformities, chromosomal abnormalities, and mental and behavioural disorders (e.g., conduct disorder, expressive language disorder). Further, these conditions were found to impact multiple systems and organs (Popova et al., 2016). However, their prevalence does not show links of causality with FASD; rather, given how common FASD is, it is to be expected that a range of other co-occurring conditions are also present. Additional research has found that the interaction between FASD and environmental risk factors (e.g., neglect, stressful life

circumstances) can increase the risk of mental health disorders later in life (Burd et al., 2003; Burd et al., 2010).

FASD Diagnosis

The Canadian diagnostic guidelines for FASD, released in 2005 and revised in 2015, summarize the critical components in making an FASD diagnosis. These include screening and referrals, physical examinations, obtaining maternal alcohol history, neurobehavioural assessments and the use of a 4-Digit Diagnostic Code (comprised of four diagnostic features, i.e., growth deficiency, facial phenotype, brain damage/dysfunction, and gestational alcohol exposure (Astley & Clarren, 2000; Cook et al., 2016). The guidelines recommend a multidisciplinary team approach for making a confirmed diagnosis, which includes a case management coordinator, a physician and/or a developmental pediatrician, an occupational therapist, a speech-language pathologist, a psychologist, and a nurse and/or social worker as needed (Chudley et al., 2005; Cook et al., 2016). This multidisciplinary approach is recommended to comprehensively and accurately determine the range and complexity of effects resulting from prenatal alcohol exposure (Chudley et al., 2005). Various diagnostic team approaches have been implemented across Canada to provide adapted services to meet the needs of the population and setting. Canadian provinces such as Saskatchewan have implemented strategies to address diagnostic assessments in rural areas, including a telehealth network (Ens, Hanlon-Dearman, Millar, & Longstaffe, 2010).

Despite guidelines recommending access to FASD assessment and diagnosis for all Canadians, higher rates of FASD diagnosis have been found in Indigenous communities. Some scholars have attributed this in part as the results of histories of colonization and

intergenerational trauma, which has profoundly affected these communities' capacity to develop nurturing environments (Badry, 2010; Koponen, Kalland, & Autti-Ramo, 2009). As well, some Indigenous communities have identified FASD as a priority area (Public Health Agency of Canada, 2005), potentially resulting in higher rates of diagnosis that are not indicative of higher prevalence rates (Badry, 2009, 2010; Salmon, 2010). This has been cited by some as the result of focusing on Indigenous women based on limited research (Poole, 2003), in addition to the social construction (i.e., an idea created and generally accepted by society) of FASD and knowledge about its prevalence amongst Indigenous populations (Ferguson, 1997; Armstrong, 2003).

The majority of individuals identified and diagnosed with FASD have been as a result of early contact with the foster care and/or correctional systems (CDC, 2004; May et al., 2013). The involvement of child protection in homes where alcohol is used (PHAC, 2010; Rock, Michaelson, Thompson, & Day, 2015), the potential vulnerabilities accompanying FASD, and risk factors for justice involvement are all contributing causes to this occurring. However, FASD manifests in every society that consumes alcohol (CDC, 2004; May et al., 2013). Recognizing the social acceptability of alcohol consumption, the high rate of unplanned pregnancies, and common misconceptions regarding the amount of alcohol that would cause prenatal brain damage is paramount to understanding how FASD occurs and addressing the social issues that arise from the disorder (Elek et al., 2013; Rasmussen et al., 2012).

Regardless, early diagnosis and intervention have been cited as an essential contributor to mitigating problematic social and/or legal issues in the future. Streissguth et al.'s (1997) work suggested that diagnosis before age six was a protective factor against the development of "secondary disabilities." The teams found that early diagnosis and interventions aid in avoiding

mental health issues, school failure, alcohol and substance use, delinquency, and incarceration (Streissguth et al., 1997; 2004). Additional research has found early diagnosis and intervention can support competency in social problem solving (Bertrand, 2009) and in facilitating early learning interventions. Further, intensive academic support throughout childhood and adolescence, and interventions can support parents/caregivers to cope with behavior, emotional, and cognitive impacts (Paley & O'Connor, 2009).

FASD and Social Implications

The diagnosis of FASD can often impact individuals' social worlds throughout their lifetimes. Challenges may include difficulty following social cues, impulsivity, and trouble understanding cause and effect. Moreover, there are common inconsistencies between individuals' chronological age and functional age; i.e., persons with FASD may function at a level younger than their chronological age (Connor & Streissguth, 1996; Olson, Oti, Gelo, & Beck, 2009). These can often result in a disparity of expectations of the individual and their ability to function at the expected level. The inconsistency between chronological age and functional age may also result in misperceptions between physical maturity and mental maturity, which can impact expectations of behaviour, academic achievement, and/or decision-making abilities (Schonfeld, Mattson, & Riley, 2005). Individuals with FASD may present as naïve and gullible resulting in their being easily manipulated in childhood and adulthood; this may also have negative effects when supervision or structure are not adequately provided (Brown & Connor, 2013; Greenspan & Driscoll, 2016; Woods, Greenspan, & Agharkar, 2011). Symptoms of FASD may include difficulties with nonverbal communication and perceiving social subtleties, which in consequence can make navigating social cues more difficult. Additional

symptoms of FASD include deficits in nonverbal communication and perceiving social subtleties, often resulting in misinterpretation of reality leading to additional issues in navigating their social worlds (Brown et al., 2011; Greenspan & Driscoll, 2016).

The negative social implications have a lasting impact on individuals affected by FASD and require accommodation and support throughout their lifetimes (Streissguth et al., 2004). Encouragingly, research has shown positive outcomes for individuals raised primarily in stable, loving environments² and with FASD-informed parents and caregivers who understand their child's neurocognitive impairment and use specialized parenting techniques, advocate for their children, and help connect them with community resources (Olsen et al., 2007; Olson et al., 2009). The provision of positive, caring environments can contribute to the fostering of positive characteristics common in individuals with FASD, such as creativity, musical abilities, and an endearing disposition (Brown, 2015). Still, this discussion raises questions about when parents and caregivers may recognize that they should reach out for support, and to whom they may reach out.

Mothers are sometimes viewed as “gatekeepers” to services, e.g., the family member who often reaches out to professionals to seek additional information or support (Featherstone & Broadhurst, 2003). Arcia and Fernandez (1998) found similar results in their research about families with children with attention-deficit/hyperactivity disorder; mothers reached out for professional support upon the realization that their children's behaviour was beyond a perceived “normative range” (i.e., mothers became aware of their children's attention-seeking behavior, immaturity, hearing deficits, or interpreted their behaviours as “lazy”). Additional factors

² Although not explicitly defined in FASD literature, loving stable environments are commonly discussed in relation to the absence of environmental risk factors (i.e. substance use by parents, physical abuse, neglect). See Streissguth et al. 2004 and Olson, Oti, Gelo, & Beck, 2009.

identified in the family support literature demonstrate that parents'/caregivers' decision to seek support can lead to unintended consequences, such as feeling stigmatized, a loss of control, and reduced self-esteem (Featherstone & Broadhurst, 2003). These issues may be rooted in how parents/caregivers define "the problem" and appraise it, through decisions for help-seeking affected by demographic or psychological factors, or through the impact of social networks (Featherstone & Broadhurst, 2003). However, a shift has occurred with some service providers identifying, developing, and offering services that are less stigmatizing and more accessible, to prevent family breakdown (Gray, 2002). Examples of these include responses that are non-intrusive and acknowledge the emotions and ethnicity of the family involved, as well as the family's views, and specific social and health care needs (Gray, 2002).

FASD, Families, and Support

It has been established that stable, loving families and residential stability are important in the lives of individuals affected by FASD. Stable home environments are amongst the known protective factors against adverse outcomes (Fagerlund, Autti-Rämö, Hoyme, Mattson, & Korkman, 2011; Streissguth et al., 2004). Despite the known importance of stable family units, families, particularly parents and caregivers and insights of their lived experiences, are under-researched amongst FASD research (Coons, Watson, Schinke, & Yantzi, 2016). Caring for individuals with FASD is a commonly stressful experience which requires significant amounts of time and energy, interruptions in familial tasks and routines, and advocating for additional resources or professional help (Plant & Sanders, 2007).

In their study of parents of children with FASD, Watson, Coons, and Hayes (2013) found four primary themes, each revealing a challenge for caregiving tasks, which include timely

diagnosis, access to services and supports, the diagnostic process itself, and behavioural issues presented by their children with FASD. Their findings also indicated that parents faced an additional barrier gaining access to FASD specialists. When combined, these factors resulted in parents and caregivers facing a distinct form of stress and strain. Earlier research by Morrisette (2001) observed seven major themes in his interviews with foster and adoptive parents related to their experiences of raising children with FASD. His findings revealed the need for constant vigilance to ensure their child's wellbeing, the subsequent effects of stress and strain on marriages, and challenges associated with management of manipulative and unmanageable behaviour by children. Additional themes included the children's struggle to conceal their disability, and the value of sequence and routine, parental feelings of inadequacy and eventual adjustment, and dealings with professionals involved in their child's care (e.g., physicians, teachers, social workers). Finally, secondary medical implications (e.g., congenital health issues, pain thresholds)³ and emancipation concerns also presented as issues voiced by the parents. Both of these studies' findings illustrate the complexity of issues caregivers of individuals with FASD face on a daily basis, in seeking FASD specialists, and supports which can best address their concerns. Additionally, these findings highlight the necessity of services which can help support both the individual and the caregivers.

Further, as a result of the range of challenges, impairments, and adverse outcomes potentially affecting individuals with FASD and their families, the response of supports and services offered should be extensive and comprise the health, education, social, and justice systems, ideally in collaboration with one another (Streissguth et al., 2004). However, when

³ For more information about medical conditions commonly found in individuals with FASD, see Popova et al. (2016).

families (biological, foster, or adoptive) do reach out for support, the options are responses can be limited (Olson et al., 2009). Bobbitt et al. (2016) identified higher stress levels in caregivers raising adolescents with FASD (compared to children with FASD aged 0-12 years) and attributed this finding to changes in resource and support available, as well as the young people assuming more adult roles related to possible employability, independent living, and the need for accessing financial support. Mattson and Riley (2000) also identified challenges of parenting during this transitional age including experiences of puberty, increased awareness of one's body, the interest in and possible development of romantic relationships, and the gradual shift toward independence. Parents stated that each of these stages was impacted by their adolescent's memory and learning impairments, executive functioning issues, levels of attention and intelligence, and language and behavioural issues, thereby making navigating this transitional time more complex.

Despite the challenges they face, families and caregivers can acquire skills and tools that facilitate raising children and young people with FASD. Coons et al. (2016), for example, examined the ways that parents have adapted to raising a child with FASD. Their findings found five central themes including their ability to learn about FASD and become advocates, day to day forms of adaptation (e.g., do not think about tomorrow; be careful what fights you pick), and transformational outcomes (e.g., reframed worldview; positive outlook). Their findings also found that the presence of informal supports (significant others, family and friends) and formal supports (FASD support groups and help from professionals) were significant. Research about the impact of FASD on families and caregivers indicates that the success of the living environments is dependent on the presence and extended access of supports, informed professionals, and structured home environment (Brown, Sigvaldason, & Bednar, 2005; Coons et

al., 2016). These findings contribute to understanding the needs of parents of individuals with FASD, and they can be used to help guide areas of intervention and support for both parents and individuals affected by FASD.

FASD and Social Stigma

Recent research has shed light on divergent discourses between how a child with FASD is viewed and how an adult with FASD is viewed (Dej, 2011). That is, children diagnosed with FASD are commonly regarded as an innocent victim or a “promising child,” with the potential to overcome challenges and be a productive member of society. FASD in adulthood may be perceived as a marker of deviance despite exhibition of the same symptoms of a child with FASD (Dej, 2011). These dynamics are not unique to FASD in particular; rather, they serve as an example of how we conceptualize ideas of responsibility, independence, and health in adulthood and stigmatize those who do not fit within these ideas. Therefore, for individuals with FASD, the transition into adulthood can be a period in which access to support services is reduced. Further, the expectation increases for the individual to adapt to the environment, rather than the environment adapting to them (Dej, 2011).

Stigmatizing dynamics are not visible solely among individuals with FASD; they have been amplified in the social construction about FASD as an “Indigenous problem” (Dej, 2011; Tait, 2009), and amongst women and biological mothers who have consumed alcohol during pregnancy (Tait, 2003). This stems from blame and shame associated with the development of the disorder (Zizzo & Racine, 2017) and can result in women not disclosing their substance use or histories to care providers during or following pregnancy, and as explored later, for fear of losing their child (Drabble et al., 2011; Poole & Greaves, 2013; Poole & Isaac, 2001). Foster and adoptive parents may experience feelings of guilt as a result of blame for “not doing enough”

if their child or adolescent's behaviour varies from norms (Buxton, 2004). Bell et al. (2016) suggest that despite little empirical research on this topic, "the burden of shame" (p. 68) encompasses non-biological parents and compels them to explain that their child is adopted (see Whitehurst, 2012).

Complex personal histories and reasons for alcohol consumption, in general, and during pregnancy, highlight part of the issue that consumption may not be openly disclosed.

Additionally, women may choose not to disclose their substance use during pregnancy fearing prejudicial actions or risk of losing custody of their children (Greaves & Poole, 2004).

Researchers suggest that women may continue to consume alcohol during pregnancy, despite information from their healthcare providers (Crawford-Williams, Fielder, Mikocka-Walus, & Easterman, 2015; Peadon et al., 2011). This may be a result of a woman not yet being aware they are pregnant, or because alcohol is a form of self-medication (Alberta Alcohol and Drug Abuse Commission, 2004; Burgoyne, 2006). A woman's decision to stay silent, rather than disclose alcohol use, may be exercised as a tool to maintain agency when faced with systems of power (Parpart, 2013; Spivak, 1988). Meanwhile, misconceptions about perceived "safe types," "amounts," and "frequencies" of consumption of alcohol during pregnancy still exist (Barbour, 1990; Walker, Fisher, Sherman, Wybrecht, & Kyndely, 2005). These misconceptions can result in women consuming alcohol during pregnancy with the misunderstanding that consumption is below a "safe" threshold amount (Barbour, 1990; Poole & Greaves, 2013).

This leads into a discussion of another form of stigma and DeJ's (2011) ideas of the deviant adult. In the case of FASD and mothers, blame is attributed to the mother's consumption of alcohol, which is made deviant and further stigmatized as a willful or selfish action. Both

FASD literature and “what works” practices have engaged in the problematic use of stigmatizing messaging in an attempt to educate women and the general public about the risks associated with alcohol consumption during pregnancy. Factors that unintentionally contribute to this stigma include health messaging that focuses heavily on preventability and women’s role in the occurrence of FASD, in addition to what has been criticized as paternalistic approaches to women’s health and pregnancy (Zizzo & Racine, 2017). Messaging about the “100% preventability” of FASD, or statements that FASD is a preventable disorder (CanFASD, 2017; Zizzo & Racine, 2017) may not recognize social realities and can perpetuate blame-based ideas of FASD being a woman’s “fault” (see Stewart, 2016). Further, it makes invisible factors that may contribute to a woman drinking during pregnancy (e.g., coping strategies, social pressures, pregnancies not yet known or unwanted pregnancies; Meurk, Lucke, & Hall, 2014) and thus further stigmatizes the possibly painful reasons why a woman may drink (Zizzo & Racine, 2017). Ultimately, blame-based prevention efforts fail to provide a contextual understanding of women’s histories, and other factors that may impact the development of FASD including smoking, nutrition and socioeconomic factors (May & Gossage, 2011).

In recent years, scholars and practitioners have moved to avoid blame-based messaging and instead have focused on the importance of implementing harm reduction supports (i.e., reducing amount of alcohol consumed, providing counselling, encouraging stress reduction techniques; Drabble et al., 2011; Poole & Greaves, 2013; Zizzo & Racine, 2017); they have also underscored the importance of partner, family and friend support (Elek et al., 2013) throughout the life course for children and mothers; clear and consistent messaging of no known safe amount of alcohol (Poole & Greaves, 2013), and importance of trusted and supportive healthcare providers (Elek et al., 2013). By raising public awareness, it is possible to reduce some of the

associated social stigma. It is also essential to create accessible and culturally appropriate recovery support services, and assistive health and social supports to women who may have had alcohol-exposed pregnancies (Drabble et al., 2011).

FASD Programming and Support Services

Beyond diagnostic work and non-stigmatizing practices, programming and supportive interventions for individuals diagnosed and families/caregivers impacted by FASD should also be considered. Continuity and supportive care of each age/life stage and the transition into adulthood with FASD is integral to reducing environmental risk factors for behavioral problems (Fagerlund et al., 2011; Streissguth et al., 2004). Further, careful screening of foster homes and disclosure of the diagnosis of FASD are important to ensuring their caregivers are both suitable and willing to care for individuals who require additional supports and accommodations than their unaffected peers (Badry, 2009; Caley, Winkelman, & Mariano, 2009; Olson et al., 2009). However, the need for support extends to adults living with FASD, who benefit from ongoing forms of support, such as stable housing, consistent forms of family and social support, and volunteer or employment opportunities (Tait, Mela, Boothman, & Stoops, 2017). Unlike support models that reduce involvement once stability has been reached, individuals with FASD are best supported with continued support and services even when stable and thriving (Tait et al., 2017). Living environments play a role during the maturation and maintenance of stable living for individuals with FASD. Highly structured, supervised, and supportive settings have also been found to reduce the likelihood of criminal involvement (Badry, 2009; Streissguth et al., 2004).

Although Canada has taken steps to develop FASD diagnostic guidelines, there has been less focus on long-term, developmentally appropriate guidelines and recommendations regarding

how to support individuals with FASD; this shortcoming is particularly pronounced for adulthood (Tait et al., 2017). As a result, the most often used treatment model for individuals with FASD aims to incorporate support, services, and structure through support workers and referrals to multiple professionals including psychiatrists and psychologists. However, as Tait et al. (2017) contend, this approach has not been effectively evaluated. Limitations also exist due to differences in available resources, programming, and supportive interventions, which vary by province and between rural and urban areas. However, researchers do find that when implemented, supportive residential living placements for adolescents and adults and provide positive support and success in community living (Brown, O'Connor, & Adler, 2012; Gerger, 2011; Radford-Paz, 2013). Such community support may include housing support, mentorship involvement, assistance with daily living tasks, transportation, and social activities. In addition, such levels of support can be customized based on levels of need of the individual, following an assessment of socialization, emotional and other needs (Brown et al., 2012).

FASD in Newfoundland and Labrador

Unlike provinces such as British Columbia, Alberta, Manitoba, Ontario, Quebec and New Brunswick, NL does not have a provincial FASD or alcohol policy that has elsewhere proven successful in facilitating work on priority areas related to FASD between government and community organizations (Dunbar Winsor & Morton-Ninomiya, in press). Thus, the Canadian Diagnostic standards and recommendations concerning interdisciplinary teams and supports have yet to receive a provincial response accessible to all regions of the province. Due to these issues, a circular dilemma presents itself in which FASD is likely underassessed and underdiagnosed in NL. Meanwhile, the lack of provincial services results in unclear avenues for patient referrals,

assessments, diagnosis, and supports. To further complicate the issue, the research literature suggests that the population most likely to be diagnosed with FASD in the province is comprised of individuals who are in residential care or in a forensic population, and who often have histories of trauma pre-dating the diagnosis (Badry, 2010; Brown, Bednar & Sigvaldason, 2007; Poole & Graeves, 2012).

These barriers further affect the ability to provide supportive interventions and services for individuals affected by FASD as well as their caregivers. The issues associated with FASD discussed above are compounded by a number of factors including the current lack of diagnostic teams under the Eastern, Central, and Western health authorities, accompanied by a lack of available supports and interventions in education, employment, and community living. Caregivers and family members often resort to gathering information to create an appropriate, supportive care regime and advocate for such care with little or no guidance. Similar challenges persist across other Canadian provinces and territories (Roberts, 2008); still, the set issues negatively affect residents impacted by FASD in NL and should not be discounted. These conditions commonly create an environment in which the caregivers are more susceptible to burnout and/or cannot meet the complex needs of the individual with FASD (Olson et al., 2009). In addition, individuals with FASD face potential struggles in daily living and functioning and may encounter limited understanding or consideration of the disability (Crawford, 2010; Douds, Stevens, & Sumner, 2013).

In response to an identified need for collaborative action, some FASD-related work has commenced in NL in recent years (Dunbar Winsor & Morton-Ninomiya, in press). Key developments include a 2008 multi-stakeholder conference joining professionals from criminal justice, education, healthcare, community-based organizations, FASD specialists, government

department representatives from all levels and foster and adoptive families, amongst others (Safer & Boland, 2008). This conference resulted in the production of a report outlining priority areas and ways to increase understanding and collaboration on FASD work (Safer & Boland, 2008). The fasdNL Network,⁴ a non-profit organization formed in 2013, has a pan-provincial structure and is funded through various provincial funding initiatives. fasdNL aims to improve the lives of individuals and families affected by FASD in the province through FASD training, education, and support groups, among other initiatives (fasdNL, 2018).

In Labrador, the Innu and Inuit governments have given priority to FASD work in recent years with the creation of staff positions to facilitate FASD work with prevention, diagnostic referral process and community supports (Labrador Grenfell Health, 2014). The communities of Sheshatshiu and Natuashish both have designated FASD liaisons, while the Nunatsiavut Government (NG) has an FASD coordinator position responsible for beneficiaries of NG in Happy Valley-Goose Bay and Inuit communities on the coast (Labrador Grenfell Health, 2014). In 2014, the Labrador Grenfell Health Authority (LGH) introduced the only multi-disciplinary FASD diagnostic clinic in the province. The development of this clinic has provided a path for physicians and child protection social workers to refer residents in the Labrador Grenfell region. As a strategy to meet the needs of a rural setting, the team has used telehealth for case consultations and team training (Labrador Grenfell Health, 2014). Such an approach could be implemented as a multi-sectoral diagnostic strategy in other areas of NL (Dunbar Winsor & Morton-Ninomiya, in press). The prioritization of FASD by the Labrador Grenfell Health Authority and Innu and Inuit governments benefit residents of these regions.

⁴ Throughout the research and writing of this thesis, I was employed by the fasdNL Network. My work and research do not directly overlap. This is discussed further in Chapter 3.

While the development of this diagnostic team has been positive, work remains to address continued challenges of assessment and diagnosis for adults and the men incarcerated at the Labrador Correctional Facility, as these groups are not eligible for referral to the diagnostic team. Meanwhile, the existence of the LGH team does not address the needs for referral, assessment, diagnosis, and follow-up care for residents under the remaining provincial health authorities (i.e., Western, Central, and Eastern Health). These three health authorities are responsible for health services on the island portion of Newfoundland (excluding the St. Anthony area), which comprises over 90 percent of the province's population (Statistics Canada, 2016). Physicians under the other three provincial health authorities are generally unable to refer to the Labrador Grenfell Health Authority, although exceptions have been made for residents who were born in the Labrador Grenfell region (J. O'Brien, Personal communication, 2017).

Under the current system in Eastern, Western, and Central health authorities, individuals with FASD and their families/caregivers are ultimately expected to engage in an often-lengthy process of requesting multiple referrals to access a variety of specialists, e.g., speech-language pathologists, psychologists, and social workers (Caley et al., 2009; Olson, 2009). For families raising biological or adopted children (as compared to children in care), this unclear and difficult process is coupled with ineligibility to qualify for respite care unless the individual with a disability also has an IQ of 70 or below. This qualifier is the limit for intellectual disability (formerly referred to as mental retardation; Department of Health and Community Services, Newfoundland and Labrador, Personal communication, 2017). Thus, caregiver burnout and increased exposure to risk factors are matters of concern for individuals and families impacted by FASD. These concerns require multiple approaches to address FASD prevention, diagnosis, intervention, and supports within the province.

FASD and Legal Implications

Researchers have demonstrated that individuals with FASD have a significantly higher likelihood to be involved in the criminal justice system than those without the FASD, owing largely to poor impulse control and deficits in decision-making (Fast & Conry, 2009, 2004; Koren, Roifman, & Nulman, 2004; Streissguth et al., 2004; Popova, Lange, Burd & Rehm, 2015; Popova, Lange, Bekmuradov, Mihic & Rehm, 2011). Individuals' trajectories through this system are often lengthy and complicated. The effects of organic brain damage, including that caused by FASD, can further compound these experiences (Burd et al., 2010; Fast & Conry, 2009). Given the enduring impacts of FASD, involvement in the justice system can be lifelong, as a result of impulsive and often delinquent or criminal behaviours, and difficulty learning cause and effect relationships (Burd et al., 2003; Conry & Lane, 2009). Brown et al. (2014) suggest that without the implementation and continuation of adequate supports and services at various points in a person's life, symptoms of FASD may be misunderstood or misinterpreted as deviant or non-compliant, and thus lead to sentencing and incarceration.

As earlier stated, the relationship between FASD and justice involvement can largely be explained by the condition's association with impulsivity and poor decision-making skills. Offences committed by individuals with FASD commonly lack planning and forethought, both of which are indicative of the brain disorder (Rasmussen, 2005). Researchers also indicate that low levels of self-control and/or impulsivity play a role regarding the types of crimes committed (Rasmussen, 2005). This was reflected in Streissguth et al.'s (1996) earlier research which found crimes against persons accounted for 45 percent of crime committed by youth with FASD, and of that amount, 36 percent was shoplifting and theft, 17 percent were assaults, 15 percent were

burglary, followed by domestic violence (15 percent). The study also found the most common age of first offence was between 9 to 14 years old. These results suggest that consistent supervision of the child or youth could protect against involvement in the justice system. For young people for whom this was absent and who already had encounters with the legal system, stable supervision could be introduced as a reactive measure, with the intent of reducing further possible involvement in criminal activity (Fagerlund et al., 2011; Streissguth et al., 2004). For older justice-involved individuals with FASD, Currie, Hoy, Legge, Temple, and Tahir (2016) found this population of adults was more likely to use substances and receive a diagnosis later in life. They were also less likely to have support workers who were FASD-trained and reported having less routine, structure, and supervision. While there are clear indications of overrepresentation of justice-involved individuals with FASD, there is no particular discerning description or profile of justice-involved individuals with FASD and those without justice involvement (Flannigan, Pei, Stewart, & Johnson, 2018). Therefore, preventing and addressing future justice involvement requires consideration of all individuals with diagnosed or suspected FASD, rather than targeting a select few from particular backgrounds.

Additional complexities to consider in relation to FASD in justice settings include the significant IQ variation between individuals with FASD. Although a higher IQ is not itself a protective factor for individuals with FASD (Streissguth et al., 1996) and may in fact place individuals at higher risk of legal trouble and confinement, having an IQ in the normal range can be coupled with disparity of verbal and nonverbal skills, and difficulties with information processing (Brown, Gudjonsson, & Connor, 2011; Woods et al., 2011). This can place individuals with FASD at an increased risk of not understanding the charges against them, the

various stages of the criminal justice process and make them unreliable witnesses (Fast & Conry, 2009; Woods et al., 2011).

Issues which may have social implications for individuals with FASD such as disparity between chronological and mental age, misinterpreting social cues, and naivety or gullibility (Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012) can also have ramifications if an individual with FASD is criminally involved (Chartrand, & Forbes-Chilibeck, 2003; Gagnier, Moore, & Green, 2011). These underlying issues may present challenges in interactions with the three central components of the criminal justice system: the police, the courts, and correctional systems. This is troubling when considering recent Canadian researchers found youth with FASD are 19 times more likely to be in prison than youth without FASD (Popova et al., 2015). The research suggests that of the average twenty youth in custody on any given day in NL (at the time of the research),⁵ three had FASD (Popova et al., 2015). In addition, Streissguth et al. (2004) found that 60 percent of a clinical outpatient sample with FASD had been involved with the law (defined as ever charged, arrested, convicted, or otherwise in trouble with the law), at a point in their lives, while 35 percent had been incarcerated. These figures, at least partially, likely reflect the criminalization of deviant or impulsive behaviours (Fast, Conry, & Looock 1999).

These findings reflect the complexities of responding to the needs of individuals with FASD who become involved in the justice system. As noted by Douds et al. (2013) in their systematic review of 1713 American court cases, the presence of a diagnosis of FASD usually negates the possibility of a death penalty sentence, but inconsistencies remain in how courts

⁵ Presently there are approximately 10 youth in custody (closed and open) in NL on any given day (Statistics Canada, 2017).

acknowledge FASD and mental health evidence more broadly. In some cases, the presence of FASD has been presented in trials as an aggravating factor, thereby justifying the imposition of harsher sanctions (Chartrand & Chilibeck, 2003). The reasoning that has been applied in these cases was based on the condition's association with poor reasoning skills, impulsivity, and failure to learn from past mistakes (Chartrand & Chilibeck, 2003; Douds et al., 2013; Verdun-Jones & Butler, 2013).

Issues regarding the role that disability should have in justice decision making broadly echo similar dynamics in society regarding conceptions and individualization of disability (Imrie, 1997). Scholars have underscored the importance of shifting focus from seeking cures and causes of disability to deconstructing social practices including attitudinal, environmental and social barriers (Imrie, 1997). In the context of the justice system, three areas of assessment have been proposed by Lindsay, Law & Macleod (2004) and summarized by Jones (2007). These areas include assessments for court (focusing on diagnosis and possible co-morbid conditions), risk assessments (offence-specific and attention to the prediction of recidivism and probability of future criminal activity), and verification of understanding the court procedures. To try to predict future risk of criminal activity, historical, clinical and offence-specific data are often compiled and evaluated. The empirical assessments commonly used and accepted have not been standardized or adapted for individuals with intellectual disabilities or with FASD. This can result in the inappropriate interpretation of results, and therefore, such assessments require the inclusion of measures for vulnerabilities including impulsivity, limited socialization, low education levels, lack of social learning and occupational skills (Fast & Conry, 2009; Jones, 2007; Lindsay et al., 2004).

Given the complex manner in which FASD affects individuals, it is imperative that justice professionals consider an FASD diagnosis throughout the entirety of the criminal justice process (Douds et al., 2013). During contact with police, individuals with FASD can be highly suggestible, at times confessing to crimes they did not commit in the hopes of “pleasing” the police or ending the interview/interrogation (Brown et al., 2011). Additional research is necessary to better understand the nature of interactions between police and witnesses, victims or as the individual charged who may also have FASD (Stewart & Glowatski, 2014). The failure to understand the intricate court process, the inability to be a reliable witness, or the act of testifying to defend themselves in court can present as additional issues. This is often the result of the combination of strong basic language skills (Gibbard, Wass, & Clarke, 2003), accompanied with initial memory encoding deficits as a result of attention and impulsivity (Mattson et al., 1996). Language and legal terminology can be problematic given that individuals with FASD can be quite skilled at repeating verbal information that they hear while lacking meaningful or contextual comprehension (Brown et al., 2011; Gibbard et al., 2003).

In correctional systems, individuals with FASD often require multiple explanations of rules, schedules, and expectations. When rules are not followed, this may be interpreted as willful disobedience resulting in consequences such as reduction of privileges (Burd et al., 2010; Fast & Conry, 2009). Research has also illustrated that individuals with FASD thrive in structured and predictable environments (Kalberg & Buckley, 2007). At first glance, the prison environment may appear to be a good fit for correctional staff who are unfamiliar with FASD; however, individuals with FASD require additional considerations in custody to prevent victimization, misunderstanding, and scapegoating from taking place (Fast & Conry, 2004). This thinking is a symptom of a societal issue, which indicates community services are not adequately

responding to the needs of individuals with FASD, and governments and organizations require additional resources to provide safe, predictable, and structured community-based environments.

Further challenges experienced by individuals with FASD in custody include the difficulty to follow social cues (Paley & O'Connor, 2009), resulting in them violating the “inmate code” or putting them at risk to be victimized by other prisoners (Ricciardelli, 2014). Then, upon release from custody, individuals with FASD may face challenges navigating their probation or parole conditions, resulting in increased levels of breaches as the result of violating court-ordered conditions (Brown et al., 2014; Fast & Conry, 2009; Roach & Bailey, 2009). This can be due to their ability to understand the implications of their conditions or with memory deficits (e.g., forgetting about a meeting with their probation officer), or consumption of substance such as alcohol (Brown et al., 2014; Roach & Bailey, 2009). Integrated supports available to individuals with FASD upon release into the community can reduce criminal persistence and support a positive reentry transition (Gerger, 2011; Radford-Paz, 2013). Additionally, individuals with FASD may benefit from more intensive community supervision (Fast & Conry, 2011).

FASD requires special attention in policing, diversion, sentencing, community follow up and interventions (Douds et al., 2013; Fast, Conry & Looock, 1999). Beyond a formal diagnosis, FASD-informed approaches should also be considered at each stage of the justice system. This requires the provision of FASD education for all justice professionals (see Stewart & Glowatski, 2014) and alternative means of addressing complex needs of individuals with FASD.

Theoretical Approaches

Theory of Social Stigma

Stigma is a persistent theme in the research literature and dialogue on FASD. Goffman's (1963) theory of stigma asserts that the effects of stigma include prejudices against particular character traits. This contributes to the subsequent development of "branding" (e.g., the presence of a mental disorder, imprisonment, addiction) and a "master status" in which the stigmatized characteristic defines that person, making invisible other positive characteristics. Stigma can affect how others (individuals or groups) perceive an individual, and how an individual perceives themselves. Notably, having a diagnosis may also impact stigma, through the creation of a 'label' or interactions with medical professionals. For some, this may require careful consideration of whom and how much information they should disclose (Bell et al., 2016; Morton-Ninomiya, 2015). Additionally, stigma can be felt by those whose lives are closely entwined, such as parents, siblings, friends, or professionals. This is known as courtesy stigma (Birenbaum, 1970, 1992) and relates to Goffman's (1963) theory that stigma can spread by association with stigmatized groups viewed as lesser, flawed, or tainted. Additionally, individuals with FASD who are also justice involved may face further stigma as a result of being a part of multiple stigmatized groups (i.e., also labelled as a criminal). Therefore, this theoretical understanding of stigma applies both to individuals with FASD and those who provide support (i.e., a parent) and may be blamed or considered responsible for the individual's disability (Ali, Hassiotis, Strydom, & King, 2012; Larson & Corrigan, 2008).

The effects of courtesy stigma may result in withdrawal, negative emotions or concealment of the disability whenever possible (Mak & Cheung, 2008). All caregivers or parents may not feel these effects equally. Birth mothers are particularly stigmatized as a result of the blame for "causing" the disability, while birth fathers largely escape the same criticism

(Bell et al., 2016; Chen, 2005; Dej, 2011). Adoptive or foster parents may feel compelled to disclose that they are not the biological parents of a child with FASD to avoid negative reactions and thereby displace blame (Bell et al., 2016; Whitehurst, 2012). Likewise, parents may feel guilt and shame associated with the process of obtaining the best interventions and supports for their child, or for not doing enough to best support their child (Buxton, 2004; Dej, 2011).

Goffman's (1963) work on stigma is evident amongst these issues, exemplified specifically about caregivers/parents and the hyper-awareness of how they are perceived. He describes this management of perception as "social information." I argue that caregivers' need to be "on" describes the way they meet the ongoing need to manage social interactions both on behalf of their child and in their role as a caregiver/parent.

Added stigma may also affect both individuals with FASD and their parents/caregivers associated as a result of the public's beliefs of a perceived trajectory toward a life a crime, poor choices, substance use, and prison. While individuals with FASD (and many others without FASD) may, in fact, experience these events throughout their lifetimes, stigma about their "anticipated trajectories" may compound issues of self-esteem and identity development (Bell et al., 2016). Issues of stigma and how it connects with FASD are complex and not likely to be addressed through a simplistic approach, instead, as Goffman (1963) posits, stigma is deep and discernable. Further, it highlights the perpetuation of stigma through enforcement of social norms and assigning blame about certain behaviours (e.g., alcohol use during pregnancy), in addition to assigning trajectories and outcomes based on symptoms of FASD. It is through this lens that I engage with developmental theory and a proposed pathway which acknowledges prenatal risk factors.

Developmental Theory

Developmental theorists have explored individual differences in criminal propensity such as the presence of mental health conditions, difficult temperaments, and their ability to affect positive parenting and teaching (LeBlanc & Loeber, 1998; Moffitt, 1993). This perspective illustrates the association between behaviour and reactions to negative life experiences, prior criminal involvement (Patterson, DeBaryshe, & Ramsey, 1989; Thornberry, 1987). Sampson and Laub's (1993; Laub & Sampson, 2003) age-graded theory, for example, examines the manner in which informal social controls impact individuals at different stages of development and the changes in criminal behaviour as individuals move through adolescence into adulthood. Adolescent informal social control is shaped by three mechanisms within the context of the family unit – attachment to the family, monitoring, and consistent discipline. The degree to which these mechanisms are strengthened or weakened (i.e., the amount of attachment, supervision, and discipline) affects the overall level of connection between the child and the family. Low levels of connection are linked with allowing or inhibiting antisocial and or criminal behaviours, while higher levels of connection through supervision, punishment, and emotional bonds can act as an insulator against delinquent behaviours (Laub & Sampson, 2003; Sampson & Laub, 1993).

School also plays an important role in adolescents' lives; varying degrees of attachment to the institution can reduce or encourage opportunities to participate in antisocial behaviour (Sampson and Laub, 1993). Social structural factors – including socioeconomic status, family dissolution, unemployment, and residential mobility (i.e., multiple living placements) – also influence the type and intensity of social bonds throughout an individual's development and can also destabilize social bonds. The later work of Laub et al. (2006) provides clear indications that

routine activities and individual agency are important considerations requiring additional research. LeBlanc and Loeber (1998) note three processes in the developmental processing of criminal involvement: activation, aggravation, and desistance from crime. According to this process, activation refers to the initial development and subsequent continuation of criminal activity (LeBlanc & Loeber, 1998).

While many developmental theorists do not explicitly discuss FASD, contributing factors of the disorder are noted, such as maternal consumption of alcohol (van Domburgh, Loeber, Bezemer, Stallings & Stouthamer-Loeber, 2009). Attention is also paid within the literature to environmental factors such as residential stability, and parental mental health and coping (Patterson et al., 1989; van Domburgh et al., 2009). Patterson et al. (1989) identify a developmental progression of antisocial behavior beginning in early childhood in which poor parental discipline and monitoring is an early risk factor. Their proposed progression eventually leads to possible delinquency in late childhood or early adolescence (Patterson et al., 1989). However, for children and youth with FASD, these potential risk factors are compounded by prenatal exposure to alcohol, and as research suggests, can add to antisocial behaviours later in life (Streissguth et al., 2004; Raine, 2004), and thus, present additional challenges from the onset.

Developmental theories have continued to undergo further specification in the nearly three decades since their initial conceptualizations. Such revisions have contributed to the additional development of themes within their theory, including risk and risk factors, developmental pathways, and proposed interventions (Farrington & Welsh, 2007; Loeber & LeBlanc, 1990; Sampson & Laub, 1993; van Domburgh et al., 2009). Assessments, risk factors are often interwoven in discussion – measuring risk factors through assessments and the identification of various intervention points in the life course. Penal strategies have been

theorized by scholars as a mechanism of managing risk, particularly a person's risk of reoffending, while also managing potential risk to the community (Feely & Simon, 1992), while Garland (2001) states that welfare approaches and tailored interventions are being replaced by risk and actuarial approaches. Risk itself is divided into dynamic risk factors, which can be altered or changed over time, such as antisocial peers, and static risk factors, which remain constant and cannot be changed, e.g., criminal history. Although such categorizations, uses, and measurement of risk itself are problematic, and not adequate in addressing corresponding needs (Hannah-Moffatt, 2005; 2016). Risk factors are central to understanding later development of risk trajectories and pathways within developmental theory more broadly. In relation to FASD and the presence of risk factors, it is imperative to combine both ideas of risk and adaptable interventions which combine intervention approaches for both static and dynamic risk factors, and also acknowledge risks associated with the presence of FASD.

Recent developmental pathways have seen a shift in focus to the earliest form of exposure to risk, suggesting a link between early risk factor(s) and subsequent risk factors and experiences (Corrado & Freedman, 2011). One such theoretical framework put forward by Corrado and Freedman (2011), incorporates the presence of prenatal risk factors, which in this case is prenatal alcohol exposure and the role that such risk factors can play in risk profiles and trajectories (see Figure 1).

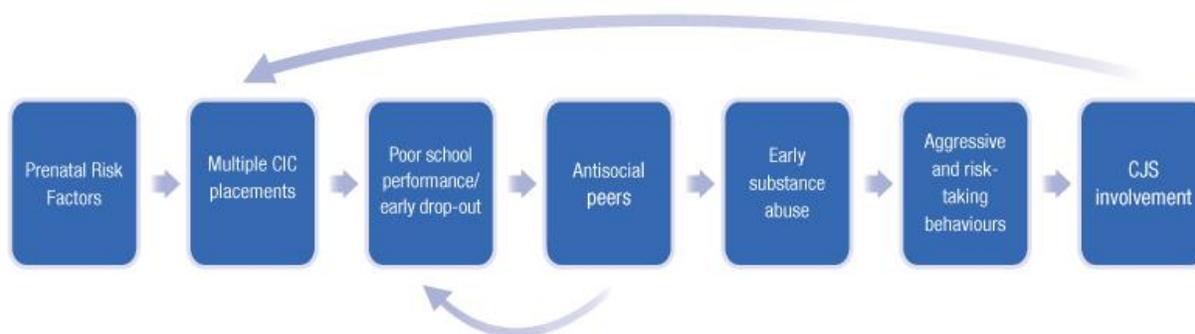


Figure 1: Proposed pathway to serious antisocial behaviour for offenders exposed to prenatal risk factors. Reprinted from “Risk profiles, trajectories, and intervention points for serious and chronic young offenders,” by R. Corrado & L. Freedman, 2011, *International Journal of Child, Youth and Family Studies*. 2, 202. Published under a Creative Commons Attribution-Noncommercial 4.0 Unported license [2011]. Reprinted with permission. <https://creativecommons.org/licenses/by-nc/4.0/>

Figure 1 above illustrates the proposed pathway by Corrado and Freedman’s (2011) indicating a possible trajectory of FASD individuals. Through this pathway, maternal alcohol consumption during pregnancy represents a prenatal risk factor for the unborn child which precedes other potential risk factors that may emerge at later life stages including poor school performance, the presence of antisocial peers, substance abuse, aggressive behaviours and ultimately, justice system involvement. Beyond the initial prenatal risk exposure, this pathway is not a linear path and individuals with exposure to prenatal risk factors (s) may be more likely to become involved in the justice system as a result of exposure to a number of additional potential factors (Corrado & Freedman, 2011; Streissguth et al., 2004).

One apparent shortcoming of this pathway is the exclusion of a stable/unstable family unit or caregivers. This may be reflective of the involvement of supportive family or caregivers, who may not be FASD aware and informed. Conversely, it could be the result of other factors such as increased likelihood of engaging in some criminal behaviours (e.g., theft) as suggested by Kempf-Leonard and Johansson (2007) as a mechanism of survival. The role of caregiver

environments and residential mobility/instability is examined carefully in my research and discussed comparatively to this proposed pathway in this thesis.

The exclusion/rejection that youth with FASD may experience as a result of poor school performance, truancy, and behavioural issues in school increases the likelihood that they will be drawn to other peers who are equally alienated (Brown & Connor, 2013; Corrado & Freedman 2011; Streissguth et al., 2004). Further, the involvement of antisocial peers can be accompanied by patterns of antisocial behaviour in which substance use may serve “as a form of sensation-seeking as a result of low arousal levels” (Putnins, 2006, p. 418). Such substance use may in turn place the individual to experience lowered inhibitions in committing crimes, or alternatively, to require money to purchase additional substances (Goldestein, 1985). Additional stressors, such as ineffective socialization and aggression in early childhood may compound these issues. During the early development years, ineffective parenting (i.e., harsh punishment, inconsistent/permissive parenting, parental rejection; Eron et al., 1991) may serve as predictors of aggressive behaviours later in life and of higher risk of involvement in the criminal justice system (Hemphill et al., 2006; Huesmann, Eron, & Dubow, 2002). However, Huesman et al. (2002) explains it how these environmental factors interact with predisposing factors (e.g., low childhood intellectual functioning, low baseline arousal; Huesman, Eron, Lefkowitz, & Walder, 1984; Raine, Brennan, & Farrington, 1997) which are correlated and not causally linked with later criminality. The pathway put forward by Corrado and Freedman (2011) accounts for the combination and compounding effects of multiple dynamic and static risk factors throughout an individual’s lifetime. Each risk factor provides an alternate critical intervention point, even if prenatal alcohol exposure has occurred, which is integral to understanding both the possible trajectory of individuals with FASD and other positive outcomes.

Goffman's (1963) work on stigmatized individuals and identity helps illuminate issues surrounding FASD as experienced by individuals with FASD and their caregivers/parents. This theoretical framework helps to explain the complexity of stigma, the role of social norms and placement of blame, stigmatizing trajectories of individuals with the diagnosis. Conversely, developmental theory and pathways provide an understanding of the need for early interventions, and critical intervention points at each life stage. These two theoretical frameworks will be revisited throughout the discussion in chapter 5.

There is currently no existing research in the area of FASD and justice-involved individuals within NL. This work, therefore, addresses this gap and contributes to the general, small body of existing literature about FASD (see Morton-Ninomiya, 2015); it also provides insight into the social factors associated with this diagnosis. This research explores a central question: *how do professionals' view risk and protective factors, access to diagnosis and supports? In their view, what factors impact the experiences and outcomes for individuals with FASD who are also justice involved?* By applying developmental theory to explore this question, it sheds light on the link between a diagnosis of FASD and navigating supportive interventions within communities throughout NL. These experiences deeply affect individuals diagnosed or working with persons with FASD and society, and this research contributes to the advancement of knowledge about appropriate and sustained forms of social support.

CHAPTER 3

METHODS

To answer my central research question, I used a qualitative approach through primary research interviews and secondary case analysis. I collected data from secondary medical summary case reports authored and provided by Dr. Ted Rosales, an international expert in FASD and pediatric geneticist. In 2015, Dr. Rosales, whom I had known professionally, offered me an opportunity to conduct research with some of the data he had amassed during his career. The information within the summary case reports was used to compile case studies, focusing on distinct circumstances of individuals who had received a confirmed diagnosis of FASD. Between 2015 and 2018, Dr. Rosales and I met on several occasions to discuss the direction of this research and the nature of the information in his reports. These conversations helped inform my decision to pursue interviews with other professionals. Thus, primary data was collected through interviews to provide a more extensive perspective on the types and extent of support in place or lacking for individuals impacted by FASD. Seven semi-structured interviews were conducted with professionals in the justice and healthcare fields, who have worked in various capacities with individuals with FASD (some of whom have been involved in criminal matters in the province). Multimethod approaches enable a researcher to consider differences and similarities between the approaches (Hesse-Biber & Leavy, 2004). Within this particular research, a multimethod approach provided personal insights into professionals' experiences working with individuals with FASD and highlighted their perspectives and experiences. Thus, these varying approaches elucidated professionals' views of mechanisms and interventions of support available or needed. The summary case reports provided a professional's view of in-depth information and private experiences at an individual level. Multimethod approaches such

as this can more robustly evaluate outcomes and amplify the possibility that unexpected outcomes, which otherwise were not considered, may be revealed (Hunter & Brewer, 2015).

Data collection of both interviews and summary case reports co-occurred during the spring of 2018. The timeline for the collection of data and subsequent analysis helped to shed light on topics, themes, and questions within the findings.

Case Reports.

The summary case reports examined for this thesis were authored and shared by Dr. Rosales, who diagnosed over 500 cases of FASD in individuals of all ages within NL before retiring from his pediatric geneticist position in 2015. In the early 2000s, Dr. Rosales undertook diagnostic work in Labrador, delivering seminars and providing clinical teaching to physicians and medical residents in Happy Valley-Goose Bay. He co-authored the Canadian Diagnostic Standards for FASD in 2005 and the revised standards, released in 2016 (Chudley et al., 2005; Cook et al., 2016). In 2005, Rosales received funding from Health Canada to conduct FASD assessments; train physicians, other health professionals, and allied health workers in FASD screening and diagnoses; and establish a data collection system (Health Canada, 2006). As a result of lack of funding and the non-prioritization of FASD work in NL, Dr. Rosales' work was largely independent and did not take place within a multi-diagnostic team approach. Therefore, the reports do not contain the input or valuable insights of other professionals usually included in a diagnostic team.

The case reports selected for analysis in this research include those of individuals who received a diagnosis of FASD and had justice involvement between 2000 and 2015. This timeframe was demarcated as a means of narrowing the results and the information contained in the reports and includes the timeframe during which the Canadian Diagnostic Standards were

developed but the revised guidelines (published at the end of 2015) had not yet been released. Further, as a result of funding received, a large number of Dr. Rosales' FASD assessments and diagnoses occurred during this period. Reports used were authored for legal proceedings, generally requested by the individual's lawyer or a mental health professional also involved in the legal proceedings. A request to have an individual assessed for FASD by Dr. Rosales would have been initiated by a lawyer or healthcare professional involved who had reason to believe that FASD could be part of the clinical picture for the individual. Alternately, if a confirmed diagnosis of FASD was already known, the legal and or medical professionals involved may have requested a report by Dr. Rosales to inform the court as to the impact and presentation of symptoms of FASD to a specific individual. Information on social supports within the reports is a significant focus of this research and includes both formal supports (such as academic accommodation, counselling or therapy programs, ongoing involvement of medical professionals), and informal supports (such as supportive family or community members, friends and social networks).

Case Inclusion/Selection Criteria

Three of Dr. Rosales' cases were chosen based on meeting a number of inclusion criteria. Such criteria included the date in which the report(s) were authored, whether the individual discussed in the report had a confirmed diagnosis of FASD by Dr. Rosales, and whether the individual had formal justice system involvement. Cases that provided detailed background information regarding residential mobility; primary caregivers throughout the individual's childhood and youth; familial circumstances; siblings; academic experiences; employment; and involvement of community organizations were closely examined. Further, only cases in which

Dr. Rosales was requested to author a report for ongoing criminal matters were considered; this resulted in hundreds of files of medical correspondence between Dr. Rosales and other medical and social professionals being excluded. Dr. Rosales anonymized approximately eight case files that met these criteria before their release for this research. Of the anonymized files, three cases, plentiful in detail and relevant historical information, were chosen for further study and subsequent coding and analysis. Information from the case files is included in the findings, in addition to a discussion about the assessment and diagnosis, and role of various forms of support and/or intervention throughout these individuals' lives. To the best of my knowledge, I do not know the individuals discussed in the case studies in a personal or professional manner. The entirety of details discussed in the case studies about their lives emerged from the summary case reports and no other source(s).

The cases included in this research documented the details of individuals' lives and what was written and documented about them. The files are not intended to provide a full narrative of these individuals' lives, nor can they offer the nuances of a personal perspective of their lived experiences. Additionally, the details discussed within the reports may not necessarily speak to the events of circumstances most significant to the individual themselves, rather, the discussion focuses on the professionals' interpretation of the individuals' life events. However, these reports provided a unique perspective on the presence of or relationship between various forms of support and the role of FASD diagnosis for individuals with justice involvement.

Measures

As one of the central concepts in this research, the presence of fetal alcohol spectrum disorder was operationalized as having received a confirmed diagnosis of FASD through medical records, physical evaluation, and confirmation of prenatal maternal alcohol use (additional

variables can be found in Appendix A). Further, the diagnosis of the disorder was based on diagnostic criteria set out in the Canadian Diagnostic Standards⁶ (Chudley et al., 2005; Cook et al., 2016). The secondary measure of importance in this research, justice involvement, refers to a history of one or more criminal convictions as either a youth or an adult or a combination thereof.

Support is commonly defined as both formal support such as involvement of professionals, academic supports in school settings, linkage to services and, access to programming and informal supports including family and friends, social integration, community involvement and other emotional bonds (Budde & Schene, 2004). However, supports will vary based on a number of factors including individual differences, the age of the individual, life trajectories, communities of origin, and cultural background. Feminist scholars have argued that the term support is so commonly used, it has essentially lost its meaning and requires disentanglement (Featherstone, 2003; Penn & Gough, 2002). Furthermore, Indigenous scholars have noted that forms of settler support have largely lacked meaning in Indigenous populations, particularly in the treatment of substance abuse (McCormick, 2000). These tensions affirm the necessity to question definitions of support and the power relationships behind how they are defined. This research engages in professionals' views of support, and not with the lived experiences of individuals. Therefore, it is important to note that when defining and discussing support, differences exist. There is no blanket definition; measures of support were based on how case reports discuss the individual and their informal supports such as family and friends. Finally, within the reports, attention has been given to any discussion of perceived support for

⁶ These guidelines were updated most recently in 2015. The case files reviewed for this study were compiled prior to these changes, and the interviews were attentive to the experiences of professionals' preceding and following these revisions, as well as any changes encountered by professionals since these amendments.

the individual by both formal and informal sources of support.

The definition of support within this research is not universal. Ideas of support and supportive interventions vary and should be culturally dependent. This also impacts making recommendations about FASD prevention and intervention work, which must be culturally appropriate (Salmon & Clarren, 2011). Finally, preliminary findings in the summary case reports helped guide additional questions that were asked during the interview process.

Procedures

The case reports were coded in spring 2018, following ethics approval from Memorial University. As abovementioned, case reports were anonymized by Dr. Rosales before their transfer for research purposes; therefore, the names of individuals, family members, and any other identifiable information (e.g., schools attended, communities in which the individual resides) were excluded. Given the relatively small population of NL, the genders and ethnicities of the individuals primarily discussed in the reports are also protected. However, gender pronouns are used to refer to the parents or foster parents of the individuals. In all cases, pseudonyms have been assigned.

The case summary reports include a variety of background information of each individual, the specifics of their home and caregiver environments throughout their lives, comorbid disorders or conditions, their educational history, significant social relationships as well as particulars of how the diagnosis was made and discussion surrounding the purposes of the report. Further, when available, the results of any psychoeducational testing or medical testing were discussed. Based on the background history available on each individual, specific information in each case varies in level of detail. Despite the files being anonymized, careful

attention has been paid to maintaining and protecting the anonymity of the individuals discussed in the cases through the use of pseudonyms and excluding specific details (e.g., a community in rural Newfoundland, as opposed to specifying the town). Possible identifying details have been removed or altered to protect the true identity of the individual(s) in the reports, which includes all references to each individuals' gender. To that end, each case has been assigned a pseudonym, which does not identify their gender (i.e., Alex), and gender-neutral pronouns were used, i.e., they/them/theirs, rather than he/him or she/her.

Interviews.

Participants

Participants who agreed to be part of this research included three healthcare professionals from a variety of professional backgrounds, three Legal Aid lawyers, and one individual in a custodial case management position. Two healthcare professionals had a specific professional focus in FASD, while the work of one centered around FASD and any number of other conditions or risk factors. Lawyers and healthcare professionals were selected for interviews through purposeful sampling based on their experience working with clients with FASD and having worked in various regions of the province. Participants indicated that they had varying levels of experience and had worked with individuals with FASD directly, through management or policy development.

Each professional was assigned a pseudonym and a general professional role description/area of the province that they worked. Efforts were made to interview professionals from various regions of the province; participants included professionals who worked or had previously worked in Labrador, Central and Eastern Newfoundland (inside and outside of St. John's) regions of the province. Finally, this research initially aimed to interview Legal Aid

lawyers and private defence lawyers. No lawyers in private practice agreed to my request for an interview, despite some having lengthy and often high-profile careers in criminal law. I spoke with several private defence lawyers by phone, all of whom were quite helpful and discussed possible reasons why they had not encountered clients with FASD. Multiple lawyers pointed out that their hourly rates could play a role in excluding any clientele without the financial means to pay. Certain lawyers provided names of other colleagues whom I might approach, however, those contacts too had not dealt with clients with a known FASD diagnosis. Additional inquiries and a review of all available case law involving both adults and youth diagnosed with FASD in the CanLII and QuickLaw databases revealed that all of the cases were represented by defence lawyers who currently or at the time of representation (prior to retirement or change of career) worked for Legal Aid. I interpret this as an artifact of the financial (in)ability of many court-involved individuals in NL to pay for a private defence lawyer.

Procedures

The semi-structured interviews took place during the spring of 2018. Introductory phone calls and emails were made through a Legal Aid directory cross-referenced with case law in databases in which lawyers defended clients with FASD (see Appendix D for the letter of recruitment). Additional contacts were identified through snowball sampling. Some contacts were identified through my work with the fasdNL Network. However, I knew or was familiar with these participants in a professional capacity only. Potential participants were emailed an invitation to participate in this research, and those who chose to participate did so voluntarily. Upon arranging the interviews, interviewees were provided with a document explaining informed consent and explained the objectives and goals of the research. The low risk of any

foreseeable harm of this research was explicated and the approximate expected time of the interview was reviewed. Participants were explained that their identities would be protected by the use of a pseudonym and a broad description of their professional title would be given (e.g., a Legal Aid lawyer). Following this, the participants signed the informed consent, ensuring confidentiality and anonymity, then the interviews began.

With participants' consent, the interviews began by discussing professional background and experience and then focused on more in-depth questions directly relating to their experiences working with clients with FASD. Various areas of discussion were explored, the interview guide served as a template for the interviews. However, many participants spoke freely and in detail about their experiences with clients and patients with FASD. These interviews complemented the case reports by providing multiple perspectives on issues arising amongst individuals with FASD involved in this province's justice and health systems. See Appendix B for this interview guide.

Interviews varied in length; ranging from 45 to 110 minutes and took place in a quiet and private setting, free of unwanted interruption. All interviews were audio recorded, with recordings securely stored on a password protected device. Following the completion of the interview, recordings were transcribed verbatim. The names of participants were replaced with pseudonyms, and the transcribed interview files were also stored under a password enabled computer throughout the entirety of the research. Upon completion of transcription, I began the analysis process by identifying reading the transcripts and identifying codes, dominant ideas, and themes, which were then focused on in further detail.

Interview Guides

The interviews with legal professionals explored topics such as diagnosis and forms of informal and formal supports in the community and interactions with the justice system (see appendix b-1). The interviews conducted with health professionals explored their experiences in assessment, diagnosis and case management of individuals with FASD, complex needs, and involvement in delinquency and/or the criminal justice system (see Appendix b-2). These interviews provided information regarding the links and gaps between health systems within NL, as well as the referral and intervention process for at-risk women and children/youth more broadly.

Two different sets of interview guides were prepared in advance of the interview process. Each guide was attentive to the different professions of justice and health. Questions focused on the professional's capacity and experience in working with individuals with FASD, their perceptions of support services offered, and how the response of justice and health systems may have changed over time. Questions were open-ended and topics include participants' impressions of criminally involved individuals' experiences of living in the community (see Appendix B-1 and B-2 for the full interview guides).

Ethical Considerations

Ethics approval was sought through Memorial University's Interdisciplinary Committee on Ethics in Human Research (ICEHR) prior to the commencement of this research. All of the individuals discussed within the case studies have been assigned pseudonyms and gender-neutral pronouns, to protect their true identity. Professionals and specific individuals (e.g., group home

worker) are referred to by broad profession (i.e., social worker; pediatrician) to avoid the possibility of identification by the reader.

During the transcription process, as described above, identifiers such as names were removed and replaced with pseudonyms or more general description. Interview participants' general profession is noted, rather than specific job title. Additionally, throughout the findings, when participants are quoted discussing topics related to specific regions of the province, they are referred to as "a participant" rather than their pseudonym to further prevent readers from identifying them.

Sensitive Data

It should be noted that the case reports and interviews used in this research contain sensitive information including demographic factors, familial details, school reports, and behavioural issues. Given the cognitive deficits and criminal history, this group is defined as a vulnerable population. In addition, the sample of interviews includes discussion about Indigenous individuals, and although the inclusion or exclusion of any ethnocultural group was not intentional, careful attention has been made not to further stigmatize an already stigmatized population (FASD) or problematize a population in limiting discussion to my own subjective understanding of their pain (Smith, 2013). The summary case reports were anonymized prior to the research beginning, any discussion of ethnicity or cultural background was removed to protect the identity of the individual; therefore, it is unknown if any of the three case studies were Indigenous or of any other minority group.

At the time of this research and for the past number of years, I have been employed by the previously referenced fasdNL Network, which is the provincial association for FASD in NL.

On a more personal level, my life has been impacted by FASD, as I am an adoptive parent of children with FASD. Thus, FASD is a topic that I am immersed in and care deeply about. These aspects combined create a space in which I have “insider” knowledge with “outsider” privilege (Wakeman, 2014) and in a position as a researcher in which I “speak” for others (Scharff, 2013). I have experienced on both a professional and personal level the vulnerability accompanying sensitive data and sharing of experiences. My proximity to this topic has provided me with the continued motivation to share the findings of this research with individuals with FASD, their caregivers, and support persons as well as professionals. Finally, my role with the fasdNL Network will also be employed as a means of distribution transfer with the Network and the general public.

Data Analyses

The summary case reports were coded using open coding. Open coding was chosen as it is a “process of breaking down, examining, comparing, conceptualizing and categorizing data” (Strauss & Corbin, 1990, p. 61). The process of coding provides an initial step of progressing statements within the data toward early analysis and interpretation (Charmaz, 2014). The information contained within reports was coded and organized using a case study research tool (see Appendix A), the development of which was informed by literature and my previous knowledge of FASD. It linked to the theoretical framework by identifying information pertinent to various life stages (e.g., familial/caregiver information, education level). Guided by the review of literature discussed in Chapter 2 and my own previous knowledge and experience with FASD, initial coding of the reports and completed research instruments resulted in three main themes – formal professional support, presence or absence of informal supports, and missed

opportunities for support, assessment or intervention. Following this, I re-read the reports and research instruments multiple times. Emerging themes, phrases and terms were identified and subsequently analyzed more closely. Memos were written as part of my examination of the reports and completed research instruments and helped inform commonalities and differences within the reports. Themes developed through an inductive approach and informed by literature on the topic (Ryan & Bernard, 2003). Through this approach, I identified the following additional themes: “Formal support and intervention points”; “Absence of informal supports”; “FASD, loss, and late diagnosis”, and “Support across the lifespan”. Additionally, memo writing during this process helped to develop additional questions and areas to explore with the interview participants.

Following the completion of a series of semi-structured interviews, as described above, interviews were immediately transcribed and coded. Themes and sub-themes were organized as I read and re-read the transcripts. Field notes made throughout each interview also helped guide the development of emerging themes. Although I was aware of the themes developing in the case studies, it was evident that themes within the interviews differed slightly.

Throughout the data collection and analysis process I consciously strived to remain aware of my own biases and personal investment in this research topic, both as a parent of children with FASD and as an employee of the fasdNL Network. My personal experiences and FASD work provincially for some time have given me a heightened awareness and made me sympathetic to the issues at play such as individual’s exposure to systems (e.g., health, justice, and community) which are at times not adequately able to support individuals affected by FASD. My close proximity to the work and research pursued in this project permitted a unique perspective and overall strengths. This was particularly evident to me during interviews with health

professionals. Many additional questions or areas to probe more fully emerged as the result of my own professional and personal experiences with information related to disclosures and medical records and health professionals' understandings of who is identified as high-risk populations within their caseload. It has remained my goal throughout this process to provide meaningful research and local context concerning issues about individuals with FASD and justice system involvement, guided by the developmental framework.

CHAPTER 4

FINDINGS

I divide my research findings into three main sections, i.e., the case study results, the interview results, and the overarching themes that were apparent across both data sources. First, framing my research with the developmental approach, I analyze the early experiences and transition to adulthood of three individuals diagnosed with FASD from Dr. Ted Rosales' caseloads. Each case study describes significant life events, the assessment and diagnosis process, and Dr. Rosales' impressions and recommendations to the courts. I organize my findings by outlining each case study, then discussing the role of formal supports and intervention points in the individuals' lives; the absence of informal supports for individuals diagnosed and their caregivers; issues associated with loss, trauma and the late diagnosis of FASD, and lifelong support. Second, I describe the interview findings, with a particular focus on recounting participants' impressions of how stigma can elevate the invisibility of FASD and its visibility within the justice system. I also discuss ideas about re-defining success through access to social supports. Third, I address how the findings from the case studies and the interviews inform one another, and the commonalities and differences within each. I discuss participants' recommendations to strengthen the province's response to and support of individuals impacted by FASD.

Case Studies

Lawyers for Alex, Quinn, and Logan (in some cases in conjunction with a medical professional involved [i.e., a psychiatrist]) individually requested summary case reports from Dr. Rosales in preparation for trial in criminal matters. Dr. Rosales diagnosed FASD in these

individuals following multiple assessments and a review of records (i.e., education, health, social, and justice systems), supplied by their lawyers, former foster parents, and/or biological parents. I describe the case study findings by focusing on four separate periods and events of their lives — early life, diagnosis of FASD, criminal history, and adulthood. The discussion throughout indicates opportunities for early interventions and stigma experienced by each individual.

Early Life

Dr. Rosales authored a case report about Alex in 2006 in preparation for their upcoming trial. The report details Alex's early life in an urban area of NL in the early 1980s. At two years of age, Alex was placed in foster care and declared a ward of the province by age three and a half. Soon after, Peter and Barbara⁷ became Alex's foster parents. They considered Alex to be part of the family and continued to keep in contact with Alex in the years after being removed from their home. Throughout their early years, Alex had limited contact with their biological mother, Ruth, through occasional phone calls and gifts. During a consultation with Dr. Rosales, Alex stated that they last saw their biological mother Ruth when they were approximately two years old. Alex recalled knowing from the phone conversations with her that "she drinks." Alex did not know their father and is aware of having multiple siblings; however, Alex does not know them. The positive connections that Alex felt toward Peter and Barbara were evident in their referrals to them by endearing nicknames. Maternal history about Ruth reveals that she had five other children. No other information was available about Ruth's other children, or if they were

⁷ All names discussed within case studies are pseudonyms (with the exception of Dr. Rosales).

impacted by FASD. Ruth indicated to social and medical systems that she used significant amounts of alcohol throughout periods in her life while she was working in NL and elsewhere. The disclosures of alcohol use during pregnancy were made in conversations between Ruth and a social worker involved in Alex's life at the time, as well as to Alex and Barbara directly during phone conversations. Additional details were not available regarding the nature of the disclosures or any role the disclosure may have played in Ruth maintaining or losing custody of Alex.⁸

Dr. Rosales' review of education reports indicated that Alex struggled in school. Alex corroborated this information and reported being able to complete basic arithmetic but stated they were unable to read. Records indicate that Alex did not complete formal schooling beyond grade six, although additional details were unknown. Ultimately, the Peter and Barbara appear to have struggled with not knowing Alex's underlying primary issues related to undiagnosed FASD. These issues resulted in Alex's removal from the Peter and Barbara's home; social workers sought other placements as Alex grew and physically matured. They stated that they were unable to cope with Alex's complex behaviours, physical stature, and noted "unmanageable behavioural concerns." Following the removal from the Peter and Barbara's home, Alex spent their adolescent years in a combination of youth group homes, youth custody facilities, and later as a young adult, in a psychiatric hospital and a provincial prison.

In contrast to Alex's case, Logan originated from a more rural area in NL. Dr. Rosales initially received a referral from a psychiatrist and other involved health professionals to assess Logan in 2013 and compile a complete clinical picture of ongoing life problems. Ahead of an in-person meeting and assessment of Logan, Dr. Rosales reviewed voluminous background

⁸ The disclosure(s) of alcohol/substance use, to whom disclosure occurred, and any formal responses to the disclosure could be a topic for future research.

information about Logan's life from several medical, social, and justice system sources, including institutional notes from previous hospitalizations and custodial sentences. Attempts were made for Dr. Rosales to conduct an FASD assessment for several years; however, it did not take place until early 2017.⁹

Logan was born in rural NL in the early 1970s and lived much of their life in a remote area. The records provided to Dr. Rosales' indicated that there were questions of neglect in Logan's life, as early as five months old. It is unclear whether Logan remained in the care of their mother, Lillian. Additionally, no information was available about Logan's father.

The available records from Logan's early life document multiple hospitalizations with healthcare professionals, as well as social and justice systems. At age six, records indicate that Logan began sniffing glue; this continued until a lengthy hospitalization at age thirteen as a result of the health effects associated with glue sniffing. Aside from health effects, records cite glue sniffing as a contributing factor to Logan's participation in vandalism in their community. Logan is also noted as having been sexually abused at an unspecified time and period in their life; the available files provide no further information about this.

Little information was available about Logan's formal education, other than that grade six was the highest grade reached. As a teenager, Logan began to engage in significant alcohol and marijuana use.

Throughout Logan's lifetime, various healthcare and social records noted issues with hyperactivity, difficulty learning, aggression, and poor socialization. Multiple psychiatrists, among other specialists, assessed Logan and prescribed medication to address some of these

⁹ Dr. Rosales agreed to meet with and assess Logan in 2017, despite being retired. Dr. Rosales had received the initial referral and documentation about Logan in 2013.

issues (i.e., hyperactivity and aggression). However, health professionals noted a history of poor compliance with their medication despite multiple attempts and interventions. Records indicate a link between Logan's reduced medication compliance and situations or periods when unsupervised.

Little information was available about Logan's parents, caregivers, or home environment more generally. Logan's mother Lillian was also from a rural area in NL and had two daughters. Dr. Rosales' report did not discuss Logan's siblings in detail. However, it does note that Logan remains in contact with one of them.

Unlike both Alex and Logan, who were both adults when diagnosed, Dr. Rosales met Quinn as a fifteen-year-old and subsequently made a diagnosis of FASD. At the time, Quinn lived in foster care in an urban centre following relocation from a rural area of the province. More than a decade after the initial diagnosis, Quinn's lawyer requested that Dr. Rosales complete a legal report as part of ongoing court proceedings in a criminal matter. In this report, Dr. Rosales recounts initial details of Quinn's assessment as a youth, aspects from childhood and adolescence, and updated impressions of FASD as it affects Quinn specifically, based on a follow up interview and assessment with Quinn as an adult.

Quinn, who was in their late twenties when Dr. Rosales authored the follow-up report, was born in the early 1980s to a young woman named Sylvia. Early records indicated that Sylvia did not have any concerns about her child's development, other than slow and unclear speech. However, health and social service professionals involved noted concerns about Quinn's development as a toddler and issued a referral for an assessment at a pediatric travelling clinic in the community. The developmental evaluation ultimately took place when Quinn was seven years old by a pediatrician.

A later assessment in another travelling clinic at age ten summarized neurocognitive and behavioural issues experienced throughout the prior decade. Testing results noted moderate cognitive impairment, continued and “totally” disruptive behavior at school which the report states as contributing to Quinn’s inability to cope with the prescribed school curriculum. Additional educational documents reveal Quinn often presented as non-compliant, angry and aggressive, disruptive and disrespectful. Educational records indicate recommendations that Quinn transfer to an altered curriculum as soon as possible. Sylvia, Quinn’s mother, stated she did not see Quinn exhibit the same problematic behavior at home as noted at school.

Sylvia and Quinn moved to a larger urban center when Quinn was approximately thirteen years old. While it is not clear what prompted the change, within a year or two following the move, Quinn began living in a group home and was part of the province’s foster care system.

Diagnosis of FASD.

Medical records indicate multiple specialists assessed Alex in early childhood and on a continuing basis as they grew up. Compiled documents provided to Dr. Rosales indicate correspondence with other professionals and multiple earlier diagnoses including attention-deficit/hyperactivity disorder (ADHD), attachment disorder, and mental retardation/delay. A psychiatrist referred Alex, then six years of age, for an assessment by the Provincial Medical Genetics Program. Referral notes indicate an assessment of a young child who experienced delayed speech, low average intellectual ability, and facial dysmorphic features sometimes found in children with prenatal alcohol exposure. The referral mentioned a strong alcohol history use, referring to disclosure made by Alex’s biological mother at an earlier date. The geneticist, a colleague of Dr. Rosales, who assessed Alex, found that they had likely experienced intrauterine

teratogens from exposure to alcohol and other drugs. However, there was no noted follow-up in the documentation provided to Dr. Rosales regarding this assessment.¹⁰ In addition to genetic testing, Alex also underwent brain domain testing twice, first at age six and again in their teen years. The results indicated moderate brain dysfunction, with seven of nine brain domains affected.

Like most children who are permanent wards in the foster care system, there was ongoing contact with social workers noted throughout Alex's childhood and adolescence. At age fourteen, a behaviour management specialist met with Alex, prompted by a referral from a social worker involved, although it is unknown if the consultation led to any meaningful changes. Further, the staff at the youth custody facility in which Alex spent time as an adolescent made extensive and insightful notes on some of Alex's main struggles (e.g., understand basic concepts of right and wrong, executive functioning challenges) and programming which could be best suited for them (e.g., importance of structure and schedule).

As part of the FASD assessment, Dr. Rosales also met with Alex and Barbara to provide background information relevant to Alex's upbringing, disposition while in their care, and reasons for Alex's removal from their home at age twelve. Despite numerous referrals and assessments, which took place years prior, Alex finally received a confirmed FASD diagnosis in their early twenties.

Logan's FASD diagnosis also occurred in adulthood, despite multiple attempts (made delayed as a result of custodial sentences and travel issues) over the span of several years. Dr. Rosales assessed Logan during a stay in a psychiatric hospital; however, Logan stated they did not comprehend the reasons for the hospitalization. Various forms of documentation

¹⁰ Alex's genetics assessment took place in the early 1990's, approximately 15 years before the release of the Canadian FASD Diagnostic standards.

corroborated information that Logan's mother Lillian had consumed significant amounts of alcohol throughout her pregnancy with Logan. It is unknown whether consumption of alcohol occurred during Lillian's other pregnancies. By the time of diagnosis, Logan was in their early forties.

For Quinn, a clinic questionnaire documented early in Quinn's life indicated that their biological mother Sylvia might have consumed some alcohol during the pregnancy with Quinn. However, no additional information mentioned a follow up assessment for Quinn.

Quinn was fifteen years old when a social worker sent a referral for a genetic and FASD assessment by Dr. Rosales. By that time, a social worker, a group home worker, a guidance counselor and special education teacher were all involved and attended Quinn's first assessment with Dr. Rosales. Each professional provided their observations and perspectives which summarized Quinn's ongoing neurocognitive and behavioural difficulties, as similarly documented by professionals involved in Quinn's early life.

Despite Quinn's reluctance to participate, Dr. Rosales was able to conduct a physical examination. Quinn alternated between indifferent to hostile towards Dr. Rosales. While the details of the examination are outside the scope of this research, Quinn's measurements indicated physical facial features found in some individuals with FASD.

At the time of the report, confirmed the maternal use of alcohol during pregnancy was a required criterion in the Canadian Diagnostic Standards, to that end, Dr. Rosales then scheduled a meeting with Sylvia, Quinn's biological mother. Sylvia was open and receptive to the meeting. In their discussion, Sylvia provided Dr. Rosales with a reasonable amount of background information surrounding her life and biological family. Sylvia disclosed significant alcohol use in periods of her adult life, including during her pregnancy with Quinn. Sylvia also provided Dr.

Rosales with contact information for her foster parents and consented to Dr. Rosales contacting them about her childhood. Sylvia's foster parents were able to provide Dr. Rosales with additional details about her behavioural and neurocognitive issues throughout her time in their care, which lasted for approximately twelve years. The conversations with Sylvia and her former foster parents provided to Dr. Rosales clearer knowledge of Sylvia's consumption of alcohol, in addition to a better contextual understanding of both Quinn's upbringing and her own. Dr. Rosales ultimately diagnosed Quinn with FASD at age fifteen.

Criminal history.

Alex's report states that their formal criminal justice involvement began at age thirteen. Previous charges and convictions¹¹ include assault with a weapon, uttering threats to cause death/bodily harm, mischief, and failures to comply with court orders. There were few details related to Alex's ongoing involvement in the justice system, nor information on the victims of the crimes, except that the assessment between Dr. Rosales and Alex took place while Alex was in remand.

Alex was able to provide some insight into their past behaviour. During an assessment with Dr. Rosales, Alex stated they had a short temper and often experienced difficulty practicing self-control. Despite this, they saw themselves as a good person and accepted they were responsible for the most recent incident which resulted in placement in remand. Alex also conveyed that their actions were the result of feeling under the threat of physical harm from individuals with whom they were associating.

¹¹ Charges and convictions were not discussed as separate within the report.

Dr. Rosales' report about Logan offered less insight into their behaviour. Rather, it detailed information about Logan's past criminal history and records of previous hospitalizations. Dr. Rosales' report provides a brief overview of their criminal history, including mention of charges for sexual offences (referring to a broad category of crime); however, it is unclear at what age they first became involved in the justice system.

Logan's report indicated a history of repeated physical traumas from fighting and accidents, which resulted in multiple visits to the hospital, accompanied by acquaintances, family members, members of law enforcement, and correctional officers. Logan's file also indicated they had attempted suicide on at least one occasion.

Unlike Dr. Rosales' report about Logan, there was little information on the nature of Quinn's criminal activity. Dr. Rosales next met with Quinn over a decade after their first encounter, when Quinn was undergoing a psychiatric assessment as part of a legal matter. Dr. Rosales assessed Quinn in the psychiatric institution while a security attendant waited nearby. Quinn stated that they did not remember Dr. Rosales. Quinn was quiet and not talkative during the assessment. Most questions asked were answered with basic replies of "don't know" and "I don't remember." Quinn provided a fuller response when asked by Dr. Rosales, replying the assessment was because "the judge said for FASD," but did not indicate if they understood the judge's statement.

Adulthood and Recommended Supports.

As an adult, Alex spent time in both psychiatric hospitals and prison. There were no mentions of employment history and no discussion of pro-social relationships, except for Alex's foster parent Barbara.

Throughout the assessment, Dr. Rosales noted that Alex was relaxed, friendly, and cooperative. Dr. Rosales' overall findings/observations note that despite the ability to recognize right and wrong, Alex lacked the mental ability to appreciate the true consequences of their instinctive or impulsive-based actions. Dr. Rosales found this to be particularly true given Alex's history of being taken advantage of and coerced to become involved in antisocial or criminal activities.

Given Alex's struggles and difficulty learning from past experiences, Dr. Rosales' recommendations included the need for a highly supportive living environment with high levels of supervision to minimize symptoms of FASD and stresses that efforts should be both intensive and life-long.

A similar discussion of the challenges to living independently and the need for supportive living environments were noted in Dr. Rosales' report for Logan. The report stated that they were unable to care for themselves and that they did not have the overall cognitive capability to "live independently without ongoing, consistent and constant support." In Dr. Rosales' view, Logan's exposure to numerous unstable and adverse environments throughout their lifetime had a significant and negative impact on Logan developing "one of the more severe clinical pictures of FASD...that I have seen in over forty years". Dr. Rosales asserted that Logan required a designated caregiver with high levels of supervision to cope with every day and common challenges of daily life. Without such support, further deterioration (i.e., adverse consequences to themselves through ongoing justice involvement coupled with unstable living and health conditions) was considered inevitable.

Dr. Rosales' report about Quinn also provided a glimpse into the environments in which Quinn lived, leading up to adulthood. However, there was limited information on Quinn's

specific life experiences in adulthood. Dr. Rosales' report states that Quinn's is a case in which the individual lacked a positive, caring, and structured living environment through childhood and adolescence. In Dr. Rosales view, the implementation of a caring and structured environment could have minimized many of the negative behavioural and neurocognitive issues experienced by Quinn. At the time of Quinn's diagnosis at age fifteen, Dr. Rosales made recommendations to the team responsible (comprised of a social worker, group home worker, guidance counsellor, and special services teacher) to ensure the provision of a consistent and caring environment to Quinn. Dr. Rosales stated that based on the information provided to him; this did not occur. The report further discussed Quinn's need for ongoing support in day-to-day living and decision-making, which are commonly expected of adults, despite the individuals' compromised functioning.

Thematic Findings

The findings of the case studies largely followed the risk factors discussed in the literature, which impact individuals with FASD likelihood for adverse life experiences. The case findings were examined collectively and the dominant themes discussed below include the role of formal supports and respective intervention points; the absence of informal supports for individuals diagnosed with FASD and their caregivers; issues associated the late diagnosis of FASD; and the need for support across the lifetime.

An absence of formal supports and missed intervention points.

Within each of the three case studies, the involvement of formal supports and the circumstances surrounding the introduction of such supports was emphasized. Formal supports within the case studies include referrals or involvement with health professionals, including

pediatricians, behaviour management specialists, social workers, guidance counsellors, and psychiatrists. Throughout their lifetimes, Alex, Logan, and Quinn were referred to multiple professionals, defined within this research as a form of formal support. These interactions with formal supports were likely helpful, as seen in the case of Logan's hospitalization for glue sniffing as a child or Quinn's referral to see a pediatrician in a travelling clinic for developmental concerns. These interactions with professionals played important roles in providing care at various points in time; however, the professionals' involvement did not appear to be ongoing or long-term. In some instances, the professionals appeared to have longer involvement, particularly in the case of Alex and Quinn whose cases noted the involvement of social workers during their time in the province's care. However, notably absent was a multi-disciplinary team approach to formal support for Alex, Logan, and Quinn. Instead, multiple professionals became involved at various points in time, largely without knowledge of a query or diagnosis of FASD.

As a result, brief formal intervention points (i.e., involved for a short period) and ongoing formal sources of support (i.e., long-term, supportive interventions throughout childhood, adolescence, and/or adulthood) differ in their ability to assist an individual. This issue was most pronounced in the recounting of Logan's substance use (i.e., glue sniffing), which began at age six and continued until a lengthy hospitalization at age thirteen. While the hospitalization remains an important and necessary form of formal support during this period, the process of detox in hospital would not suffice to provide long-term formal support. Once released and sent home to another region of the province, follow up contact and continuity of care would have been more challenging to maintain. In Logan's case, the glue sniffing and substance use continued following return to the community. No long-term formal supports were noted once Logan was released from the hospital and returned home.

An absence of informal supports.

Beyond the challenges associated with limited formal supports, all three individuals' files indicated family members, including parents and/or siblings, with whom they had never met or no longer remained in contact. This was likely a result of their placement in the foster care system and the challenge to place sibling groups together in the same home. Further, it is not clear whether Alex or Logan re-established contact with biological family members later in life. An exception to this was Alex's relationship with their former foster parents Peter and Barbara. Alex's lasting bond with them also coincided with what appeared to be one of the most prolonged periods of residential stability and educational success based on Dr. Rosales' case notes. Following the removal from Peter and Barbara's home at age twelve, Alex did not complete any further formal education and soon became criminally involved. In Alex's case, the file suggested that their parents also lacked the opportunity to create informal support bonds with other caregivers of individuals with FASD, a recognized form of informal social support (Coons et al., 2016). Peter and Barbara had invested years in raising Alex and were otherwise capable of raising an individual with complex needs. Still, as stated earlier, this caring environment was ultimately terminated as a result of Alex's unmanageable behaviors.

Logan's case does not explicitly state whether they were placed in foster care; however, numerous documents referenced by Dr. Rosales point to adverse living environments for the entirety of their life. Further, there is little indication that interventions were made throughout Logan's development to provide improved levels of support. Quinn was removed from mother Sylvia's care when they were approximately thirteen years old and soon after relocating to a different city with Sylvia. Thus, Quinn's experience of being removed from their biological family and a loss of contact from siblings, and Alex's experience of being removed from a happy

foster home placement, coupled with new, short-term living environment (e.g., group homes and youth custody) likely resulted in reduced capacity to form new or strengthen already existing informal supports or networks. The instability of their living environments highlights yet another risk factor discussed in Corrado and Freedman's (2011) developmental pathway and the failure to provide early supportive and lasting interventions, which will be discussed in greater detail in chapter 5.

FASD and late diagnosis.

All three individuals received a confirmed diagnosis of FASD in their early twenties, early forties, and mid-teen years respectively. At which time they had experienced multiple forms of instability during their lifetime through various types of abuse, neglect, school failures, residential instability, and lack of informal supports. Living and school environments in which caregivers and educators did not know how and/or lacked the appropriate tools and resources to support them best likely compounded these issues. Early supportive and long-lasting interventions were not implemented or sustained throughout their lives. Further, additional resources to support caregivers may have strengthened or lengthened the time that Alex spent in a stable living environment such as the home of Peter and Barbara. Meanwhile, Quinn and Logan would have benefited from supportive interventions before their subsequent justice involvement. However, the individuals' experiences of residential instability and the unawareness of FASD by professionals and caregivers involved likely contributed to missed opportunities to effectively support Alex, Logan, and Quinn. It is expected that the stigma associated with maternal drinking during pregnancy and FASD itself greatly impacted these

missed opportunities for assessment, diagnosis, and intervention, as I explore in the forthcoming discussion.

Support across the lifespan.

Clear indications were visible that Alex, Logan, and Quinn struggled to meet the expectations of their chronological age, experienced both behavioural and neurocognitive issues, and had difficulty with formal education and employment. Largely overlooked or absent were alternative/non-traditional approaches to provide support. Alex, Logan, and Quinn each spent time in various care placements and medical/social/penal institutions, signaling that they required supplementary, and more refined supports, beyond the brief interventions offered by the professionals involved. The lack of accommodations to support these three individuals as children, youth, and adults may also be related to the later diagnoses of FASD; their struggles may have been interpreted as behaviours/issues they would eventually mature beyond. More notably, based on Alex, Quinn, and Logan's patterns of decision making as adults, it was evident that they each required support in daily living and supervision supports which were not in place them. Dr. Rosales' reports underline the fact that these individuals would not outgrow their challenges, or at least their need for support. Rather, a glaring commonality exists between the three cases: the urging that Alex, Logan, and Quinn all required high levels of ongoing supervision, support in daily living and life decision-making.¹²

¹² Summary case report were written ahead of a trial and/or sentencing. It is unknown if and to what extent the court took Dr. Rosales' opinions into account when deciding the sentencing, or developing terms of probation or community follow up for Alex, Logan, and Quinn.

Conclusion.

These findings reveal the experiences of three individuals who experienced a multitude of challenges and barriers throughout their lives, in part as a result of being impacted by FASD. All three case studies echoed commonalities related to the inconsistent availability of formal supports and the essentially absent informal supports throughout their lifetimes. Again, this reflects missed opportunities for early supportive interventions throughout their development. Similarly, Alex, Logan, and Quinn experienced multiple forms of loss early in their lives and received their FASD diagnoses later in life (i.e., in adolescence and adulthood). By this time, they had already experienced multiple residential placements and became criminally involved. As discussed in the literature on the topic, diagnosis and accompanying interventions have proven most effective when implemented early in life (Bertrand, 2009; Paley & O'Connor, 2009; Streissguth et al., 2004).

Next, I will discuss the findings from the interviews, followed by a discussion of how they complement the findings from the case studies.

Interviews

The findings of the interviews illustrated the complexity of FASD, stigma, and diagnosis within NL. Dominant themes from the interviews include being self-taught about FASD, diagnosis as a roadmap or currency, inadequate formal response and support, and visibility/invisibility of FASD and stigma. Additional discussion related to healthcare and justice professionals' perspectives are discussed, followed by a final theme – re-defining success through social supports.

Thematic Findings

Diagnosis as a roadmap and currency.

Interview participants spoke in various contexts about FASD diagnosis and what a diagnosis can and cannot provide to impacted individuals, to their caregivers, and to the professionals who are working alongside them. Exploration of the topic of FASD diagnosis highlighted the importance of a confirmed diagnosis in community and court proceedings. Further, that a confirmed diagnosis of FASD can act as a roadmap to services, serving as a guide to implementing academic accommodations, parenting strategies, level of supervision, and referral to professionals. Additionally, it can also serve as a form of currency, particularly in legal proceedings, in which it gave defence counsel the ability to argue reduced moral culpability and more lenient approaches. Participants stated that such information should be included as a detail in probation officer's presentence reports, in their interactions with Crown counsel, and in the lawyers' sentencing submissions to the judge. Participants acknowledged the importance and need to have access to diagnostic teams in various regions of the province. However, Evan, a Legal Aid lawyer expressed that conversations about whether their client had FASD could be uncomfortable, "it's not a nice conversation to have with somebody 'do you think your mother drank too much while she was pregnant?'" Despite this, Jake, also a Legal Aid lawyer, stated that having a confirmed diagnosis strengthens the possibility of a judge taking FASD into account:

I would be able to advocate more for the client, for a more lenient defence, more lenient treatment, and more rehabilitative treatment. And it would not fall on deaf ears, but based on suspicion and what I think, if I go to a Crown and say I think we've got an issue, I would get rebuffed more or less.... if I have a confirmed diagnosis, it puts some meat on the bone of that argument.

This sentiment was expressed by another legal professional who discussed the differences between a suspected diagnosis and one that is confirmed:

A lot of times, I can go to the Crown that they [the client] have FASD and they'll say, "where's the proof, do you have the diagnosis?" so a formal diagnosis helps negotiate better and also to bring that before a judge or whoever is working on the sentencing, they would definitely take that into account. And it's not an excuse for behavior, but it can provide some explanation.

In this statement, there was the acknowledgement that an FASD diagnosis is not intended to create an excuse for the individual's behavior or past choices; rather, it provides context about this individual's life and provides some answer to the "why" behind some of their challenges. Additionally, the presence of a confirmed diagnosis and necessary supporting documentation of previous assessments or health records can also provide the court with an indication of the level of impact that has been caused by FASD. Interestingly, the case manager interviewed stated that a formal diagnosis of FASD played less of a central role once in custody. Rather, an FASD query or evidence of FASD behaviours was sufficient to provide additional instructions and support. The participant further explained that prisoners received FASD training, along with staff.

In the community, a diagnosis of FASD was explained as bringing some relief and acting as a roadmap to services; one healthcare participant described it as "the aha moment." A moment which answered their questions and opened the door to formal educational responses, such as academic accommodations (i.e., the development of an Individual Education Plan [IEP] in the school) or the use of visual schedules, visual reminders, and other resources within the home environment. Emily explained that for many families she interacts with, the diagnosis is the beginning of a new set of challenges, such as navigating the role of advocate, seeking support, learning about FASD, and accepting the diagnosis their child has received. Further,

delineating the behaviours that are attributable to FASD and the behaviours that are attributable to histories of trauma can be a particular challenge for professionals and caregivers involved. Participants' discussion reflected that the diagnosis of FASD should serve as a pathway rather than a destination.

Inadequate formal response and support.

Beyond issues of diagnosis, participants reported a general lack of formal support responses for individuals impacted by FASD and their parents or caregivers. The healthcare professional involved in maternal and prenatal health identified the issue of inadequate screening of pregnant women. One participant discussed a program that public health nurses across the province can implement as soon as a pregnant woman has agreed to a referral. She described the resource, known as the BABIES (Before Birth and Beyond: Information, Education and Support) program, includes an in-depth assessment designed to detect areas of need and provide necessary assistance for all women in the province who have consented to have a public health nurse visit them. Further, the tool provides opportunities for in-depth, private, and non-stigmatizing discussions between nurses and patients. Under the Central and Western Regional Health Authorities, this tool has seen a fair amount of success related to participant response and levels of disclosure. Public health nurses in Labrador Grenfell Health have also adopted the tool. The participant further stated that in the Eastern Health region, with the exception of St. John's, there is an identified shortage of public health nurses which has resulted in the assessment tool only being used if women are already identified as at risk (e.g., part of the methadone program; have applied for the mother/baby supplement program). One participant stated that women who are missed through screening by healthcare providers:

If we get beyond the stereotype of who out there may drink alcohol during pregnancy, it's often the one that we are not suspecting, and that person is totally missed [without proper screening], unless they're in poverty or they sought help for other matters, they're not going to be supported in that piece about alcohol and pregnancy.

As revealed in the quote, this participant recognized that stereotypes affect us all, including healthcare providers, however, in this situation, preconceived notions of what type or group of women would drink alcohol during pregnancy directly impact the screening and subsequent care and level of health monitoring that the woman and her baby will receive.

Olivia, another participant who has worked closely with families impacted by FASD echoed the need for additional formal support, described families need for support, particularly immediately after receiving an FASD diagnosis:

There needs to be more for the families after they get diagnosed, but I don't know where that falls... it's so frustrating for these parents, for these foster parents, I've seen this in my previous role as well as a [previous employment role], these kids can be so frustrating to work with and it's not because they are frustrating, it's just because some of the behaviours that they're exhibiting, we can't understand. And we say, "why are you doing this?" and it's so frustrating, so I think if you had a therapy that was designed for you know, in the home, and someone to explain, this is why they're doing this... So, I think that's the piece that parents and foster parents, or guardians are struggling with.

Olivia underscored the fact that having a diagnosis of FASD is not, in itself, enough to provide meaningful support for caregivers (see Morton-Ninomiya, 2015). As she explained, caregivers are no less frustrated by the challenges presented by FASD in their day-to-day lives due to having a diagnosis of FASD. In Olivia's view, adoptive parents¹³ experience additional gaps in formal support as they rarely have continued access to social workers and relief workers that foster families may have while caring for children in care under the Department of Children,

¹³ Olivia discussed adoptive parents, as she works largely with adoptive (or foster parents), however biological parents/families would face very similar resource challenges as adoptive parents in NL.

Seniors and Social Development (CSSD). Additionally, to receive formal supports, such as respite, adoptive and/or biological families would be responsible for the financial costs:

It's unfair to some degree that unless you're on a protection caseload, certain services aren't readily available to you. It's a lot easier for a child in care to access, there is more pull behind that case, they have a full organization behind them but if it's just a mom that's adopted her child and ten years later finds out the child has FASD, its ok, now what, you're just a parent, you're left fighting for them. They are your child no doubt, but just because the child is not in care doesn't mean you shouldn't have the same resources at your disposal.

Olivia's comments described the different challenges faced by adoptive vs. foster families in the province. It is this dynamic she said, that impedes some foster families' willingness to adopt, despite the families having the same foster children in their care for years. The process of formal adoption would likely remove or limit the formal supports already in place, thus, likely placing additional stressors on the parents.

Legal professionals also identified a need for additional formal supports, particularly during vulnerable periods of transition. One such period is while awaiting trial:

There are huge gaps, and a lot of times, for someone to be released from custody, they'll need a bail plan, they'll need a surety, they'll need a place to live, and some clients just don't have those things. If we can't come up with a good enough plan, they'll just stay in custody until their trial matter is heard and that can be months.

Here, Susan, a Legal Aid lawyer described the use of remand custody in the province due to a lack of community resources and programs intended to support individuals who do not have informal supports in place (e.g., a surety) that can ensure their release from remand, or the formal support resources to act as sureties (see John Howard Society Ontario, 2016).¹⁴ Another

¹⁴ Multiple participants mentioned the John Howard Society and their ability to provide bail and sureties in other Canadian provinces. See John Howard Society Ontario for information about their Bail Verification and Supervision Programs.

participant, Emily, identified additional gaps in formal support including the fact that many of her clients with FASD do not have Social Insurance Numbers, another form of government identification, or employment history. Granted, all issues that existed before the individual became criminally involved, nonetheless, they have been left unaddressed and are compounded as custody release plans are made, or individuals attempt to transition back into the community. It is circumstances such as these that led another participant to state “these people are forgotten about.”

There was a discussion amongst participants of some positive formal supports now in place for residents in the Happy Valley-Goose Bay region, including the Nunatsiavut Government’s supportive living programs that two participants spoke of very highly:

I think they’re [people with FASD] at a disadvantage; there are certain programs...the Nunatsiavut Government seems to have a lot of really good programs right now and assisted living places where I think people with FASD can live and be supported. There’s a care worker there but some other people kind of fall through the cracks.

This legal professional acknowledged the vital work undertaken by the Nunatsiavut Government to offer assisted living units for individuals with complex needs, including FASD. Another participant provided nuances about challenges faced by some individuals who want to return to their home communities with their families and thereby have to choose between formal supports offered in Happy Valley-Goose Bay or familial attachments and informal support in their home.

Most of them have been in and out of care, so they’ve often been home and they tend to still have those connections to family [biological], it’s not healthy... a lot of times, but they tend to always go back to their biological family, to their home community, which tends to be a very bad situation but they seem to be pulled back to that and that’s where they want to go, many who have even been offered to get set up in a different area, they just refuse, “nope, gotta go home, gotta take care of my mom or my dad.”

Multiple participants identified the need for additional supportive living units – across all areas of the province. Emily stated:

The support must be offered within the communities, because there is that pull, that these guys want to go back. So, if somebody is coming from [small community] or [small community], then I have to say, listen, this will really be helpful to you but you have to come to [city away far from their home community] and a lot of them don't want that or it doesn't work, because they just want to go home. So, it has to be supported living, in their communities.

The role of familial supports, when present, appeared to play an important role, particularly in Indigenous populations. One participant explained:

They're [supports] overall lacking, but I will say in Labrador, compared to other places, I feel like they have a lot of family supports. So even if there's a family and three of the seven kids, three of them are in custody, if one of them is before the courts, their Mom and Dad and their brothers and sisters will all be there, trying to support them.

Thus, fostering informal supports and maintaining familial relationships in addition to providing options about where individuals can access formal support become a key part of the discussion. This may be particularly important when individuals' informal attachments, such as family, are in rural areas of the province.

Visibility/invisibility of FASD and stigma.

Invisibility and stigma in the health system.

Participants in both the health and justice fields referenced FASD using notions of an invisible issue. These ideas of visibility or invisibility about FASD closely connected to ideas of ongoing stigma experienced by individuals impacted by FASD or their biological mothers. For healthcare professionals, the general public's perception that FASD is not a problem in their community contributed to ongoing stigma. Olivia spoke of the challenges faced in a community where she works when she encounters individuals who identify FASD as a non-issue, "I don't

think FASD is something that is on top of people's minds, I don't think it's considered."

Moreover, Olivia reported that in the largely non-Indigenous community where she works, FASD was commonly viewed as an "Aboriginal problem".¹⁵

I go to [small community] and people say, "oh that doesn't happen here, that only happens in Labrador" people are racist about it, that its only women who are Aboriginal, who are drinking and don't care and I think there is just a big stigma on these kids, that we already know what you're going to be.

Olivia described the issue of FASD as "out of sight, out of mind" and elaborated further, explaining that FASD has been known about for years, but it is not often talked about unless you work in the field.

Another healthcare professional, Abby, identified the challenges associated with healthcare providers building trust and being able to talk openly and non-judgmentally with pregnant women as a way to address stigma and accurate reporting of the number of women using alcohol in pregnancy in the province. Healthcare professionals, who were tracking this information, knew that self-report data was underreported "we had such low levels of reporting, and we knew it was happening out there." For Abby, issues of stigma and interactions between healthcare providers and pregnant mothers who fail to carefully explore the topic are a source of subsequent problems. In Abby's view, the absence of / reluctance to disclose resulted in reduced future identification of FASD issues in a child, reduced access to services for mother and baby, and reduced provincial reporting of alcohol in pregnancy by healthcare providers:

Our biggest problem is identifying and enabling women to feel comfortable in stating that they're using alcohol in their pregnancy. So, we've got to get better at that, we've got a way to go with that, and a lot of time was spent in trying to educate care providers and how to ask the questions in a sensitive way, in a non-threatening sensitive way.

¹⁵ I use the term Aboriginal throughout the findings and discussion chapters to mirror the word choice of my participants.

Abby expressed concern that without open dialogue about alcohol and pregnancy, women are less likely to disclose, fearing stigma and losing access to their baby. Once again, these topics connected with the idea that by disclosing, a woman was making herself visible, to be stigmatized and to risk the involvement of agencies which have the power to remove their baby:

We all know it's women's fear of losing the baby, that prohibits them from being open. So that's the first step, we need to get better at that. And we need to find a way that women are more comfortable and feeling supported without losing their child...the next step is to determine if a child in due course is going to be diagnosed with FASD.

Another consideration in the discussion of FASD as an “invisible” issue was concerning physical symptoms, which may not manifest in pregnant women or their newborn babies with the same visibility that drug use may. A recent focus in the province on illicit drug use during pregnancy has resulted in amplified public, media, and governmental attention. Abby pointed out that it can be much more difficult to detect alcohol use in a pregnant woman or a newborn baby prior to release from hospital:

I can go in [to the hospital], I'm a professional, I can tell people I don't drink, have my baby, you [health professional] might not notice anything, I go home and it's only when my child goes to daycare or school [that it becomes evident]...and my child is displaying some behavior that people are questioning...So, the mother who is addicted to opiates, often, even if they don't admit to using, your baby will show signs of withdrawal in hospital when you're there for a couple of days, and people are attuned to that, so if you've got a baby that won't settle with a shrill, piercing cry or a baby that could be very jittery, well people [health professionals] look at that...you're going to watch this baby and put all the pieces together, and maybe go back and have a talk with mom and see if she has been using any substances or medications, but alcohol babies, you won't see any of that so, the substance use, right now has captured much more of media attention, much more government attention, much more healthcare attention because this is taking resources in acute care settings.

As a result of the differences or absence of physiological symptoms, the delay in noticing an issue amongst babies born exposed to alcohol versus those exposed to drug use can result in years passing before detection of behaviours in the child or disclosure of alcohol use by the

mother is known or assessed. It is also another manifestation of how the visibility of FASD and stigma remain pervasive. Further, the ability for detection and follow up with new mothers and their babies connect with the health care system's capacity and the availability of and process of obtaining formal supports.

The need to seek out supports and resources often takes place several years later, once symptoms of FASD begin to emerge. William, a health professional spoke of the lack of attention and resources available for families impacted by FASD, he stated:

There is a lack of resources because this [FASD] is not a life or death diagnosis, so mostly the family community is left on their own unless somebody takes it [FASD as an issue] up...they don't get much of any kinds of resources, so the parents basically are the advocates to get special resources or professionals involved.

William's point highlights his view that burden of seeking resources and support largely falls on the shoulders of the caregivers, who are required to independently educate themselves and seek information about FASD and their child's needs, as a means of requesting and possibly obtaining formal responses for support. Further, caregivers often become the "expert" about FASD, explaining or clarifying information about FASD to professionals involved in their child's care.

Visibility of FASD in the justice system.

The topic of visibility of FASD is also evident in discussions with justice professionals, particularly when seeking additional information about a suspected or possible diagnosis of FASD in an individual's past. Susan, whose client caseload at any given time includes approximately ten to twenty clients with confirmed or suspected cases of FASD, stated that the boundary between finding confirmation of an FASD and privacy issues of health records and right to privacy as a complex area, "us as lawyers, how far can we go in asking someone about their health, you know what I mean? Or getting their medical records...it's all very on the fly."

Susan also discussed the importance of including information about an FASD diagnosis as part of sentencing submissions in court proceedings:

We do get a pre-sentence report, so a lot of times a probation officer will call up a client and get some information and sometimes they'll call the mother who might say "oh I drank while pregnant, and they have FASD" so that's one way we get it in [to court proceedings] but we rarely get expert reports or anything.

However, Susan acknowledged that probation officers also encounter barriers to obtaining information for pre-sentence reports. When she realizes additional "digging" must be done to receive confirmation of past FASD diagnosis, Susan stated she would interview the client, and bring the information to the judge herself. Thus, making the FASD diagnosis visible to the judge and Crown counsel during court proceedings is of significant importance to lawyers defending clients they know are impacted by FASD. Conversely, another participant Evan explained that he has seen a diagnosis of FASD combined with a history of impulsive decision making has resulted in the Crown arguing for remand:

At bail hearings, a history of inability to have impulse control, diagnosis...have to be remanded, this person can't keep the promises that they're making...whether that's on the record, or whether everyone knows that's what's happening or it's not on the record...yes, I've seen that [FASD argued to be a contributing reason to be remanded into custody].

Excluding pre-sentence reports, several lawyers spoke of the challenges of obtaining expert opinions or assessments of their clients, particularly in rural areas of the province. Jake referred to the process of trying to make a diagnosis such as FASD visible before the court as particularly complex and challenging:

With this particular issue, it's the cart before the horse, the person has to give consent to let me get the help, so you can't force it [assessment] upon anybody, so when someone [a client] comes to me and says, my parents say I have these issues, I would recommend they go see a social worker or a psychiatrist, but we don't have the resources here in rural Newfoundland to do that...those resources are simply not here.

The issues encountered by both health and justice professionals in these instances highlight stigma, right to privacy, consent of the individual, and access to resources as additional barriers to provide appropriate responses for both for adults with FASD involved in the justice system and in addition, women during pregnancy or with young children impacted by alcohol exposure.

Healthcare professionals' perspectives.

Healthcare professionals participating in this research spoke of the “layers” of the issues of pregnancy and alcohol, FASD, and stigma. The health professionals interviewed for this research worked in various regions of the province, and in differing areas of focus (e.g., prevention, diagnosis, and intervention). Despite this, their discussion often returned to statements reflecting the complexity of addressing FASD, and the need for additional formal supports for pregnant women, individuals impacted by FASD, and their caregivers. In the final stages of the interview, each participant was asked to identify areas of need and recommendations, which in their view could assist in improved response and provision of formal or informal supports in NL.

To screen all women, all women in the province need to be screened for alcohol, for substance use, tobacco, for emotional issues. Every woman requires a good assessment, I think if we could have that done and if women could feel talked to in such a way that they didn't feel threatened to lose their baby, to disclose... The other thing, of course, is that education about alcohol use and pregnancy has to continue, the public and population health messaging.

Abby's statement also spoke to the need for a two-pronged approach – (1) a general need to provide accurate information to the general public about the risks of alcohol and pregnancy in a non-stigmatizing manner; and (2) to screen all women who are pregnant in the province.

Olivia echoed similar sentiments about FASD prevention work, despite working in an area of FASD work that is less focused on prevention; she stated that reactive interventions fail to address the root of the problem. Thus, prevention work should be adequately addressed:

We are so far away from being comfortable and depending on who the patient is, doctors don't want to ask, don't want to offend anybody. I think there are layers there that we're not [dealing with], we're just dealing with surface stuff, we are not going into any preventative work.

William, another participant, pointed to the importance of education as well, stating "alcohol is part of a lifestyle...it becomes really a matter of education, and then choice." Here, he recognized the importance of formal responses, such as increased public awareness initiatives as well as the personal choice of the individual. He identified families as playing a key role in providing informal support, both partners, and extended families. William stated that one concrete manifestation of such support is partners and families' ability to abstain from alcohol during a woman's pregnancy (see CanFASD, 2014).

Justice professionals' perspectives.

Lawyers participating in this research spoke of the importance that a confirmed FASD diagnosis versus a suspected diagnosis has in their ability to present all of the pertinent facts of their case and reach the best outcome for their clients. However, three common issues clearly emerged. The first was the variability of types of crimes committed by individuals with FASD. Susan described the crimes committed by her clients with FASD as "all over the map," ranging from common assault to serious sexual offences. She noted that it was very rare to see any type of planning of the crimes; instead, the individuals' actions were impulsive and linked with alcohol intoxication. Susan explained that this resulted in many clients being unable to

remember any details of their offence¹⁶. She did point out that they do generally exclaim how sorry they were for their actions.

The second issue that emerged was participants' realization that their clients did not entirely comprehend the court process and their various attempts to explain the process and "talk to them at their level." Despite using basic language and explaining what step would take place next, some lawyers explained this was not sufficient. Compounding the difficulties in understanding the court process was that many clients with FASD were unable to recall their crime(s). Jake spoke of the need for additional resources to help guide these clients throughout each stage of the court and justice process:

The court demands insight, they want to see that you have insight and these individuals are just incapable of insight in a lot of situations, and there is no resource here. A simple mental health case worker to help explain to them, to give them the context and to follow up with them. The people I deal with, just seem so isolated.

This struggle to understand the legal process also translated to challenges comprehending and following their court conditions. Susan summarized these two key issues by saying:

One, they [her clients with FASD] don't really understand the [legal] process about everything. Two, they're on conditions and they find it really hard to sift through them, for instance, there might be a condition to stay at this house, and then they can't live there and might have nowhere to go so they have to go to a homeless shelter, so if they have nowhere to live, they might be breaching. Another is a lot of these individuals have trouble themselves with alcohol addiction problems, so sometimes they'll [the court] put them on no drinking conditions, and then they're original charge gets dismissed but by the time they go through the system, they have eight or nine breaches.

¹⁶ Three participants spoke of the use of R.C.M.P detachment lockups in rural and northern areas. They expressed concern about extended periods that individuals can be held in lockup, in some cases up to a few months, and that the facilities are not equipped to provide kitchen or recreation spaces. Further, they cited overcrowding at times and conversely, isolation of no other individuals as additional concerns. One participant stated "I'm amazed that it's not more of an issue, or how it hasn't been made public, because there are people who have spent an exorbitant amount of time in those lockups, and they're not a place for that, they're not made for that, and they're not meant for that. And... a lot of times it's just that we have a very complacent population of guys who just do their time and don't complain. But if the right person complained, I think that would be huge."

I asked Susan about the ramifications if an individual has charges against them dropped, but they have incurred administrative charges during the pre-trial period. She provided an example of a common scenario in her practice:

A lot of times, two people might get into a fight and on the day in court, one might say, I don't want to go ahead with these charges, or a lot of times the Crown can't prove the case [so the charges are dropped], but in the meantime, they're [the client] waiting...eight months for trial and they're put on no alcohol conditions, so in that time, you know they get caught drinking once a month so then they go to lockup for the night. They get released and then they have to go to jail for all these breaches...I see it all the time, they'll have breaches and they'll have to serve 90 days, just for breaches, it's a messed-up system.

These occurrences largely result in the cyclical pattern of breaching, being placed in custody, being released from custody, incurring additional breaches in the community, and then returning to custody. This cycle, although not uncommon for individuals without FASD as well, is further compounded by the individuals' challenges in understanding their actions, the legal process, and secondary challenges they may experience (e.g., alcohol dependency). Secondary challenges, such as alcohol dependency further complicate the cycle as a result of the compulsion to consume alcohol, despite possible consequences (e.g., a breach). The number of breaches of this nature also result in a frustrating cycle for the lawyers of clients with FASD, one participant stated, "it's just ridiculous, we are spending all day trying to get people out on bail so that their trial matters can go ahead, it's a total gong show." Emily stated this type of situation happens "all the time, it's extremely common and the guys know it, a lot of them and they will say:

If they didn't keep giving me these conditions, I wouldn't be here." And I've heard them even say it to the judge "don't give me conditions, I'll breach it" they seem to comprehend that this is going to trip me up and they will tell the judge that as well...they know they're not supposed to drink but....

Two participants stated they have seen a shift in the Happy Valley-Goose Bay area, in that some judges are now altering bail conditions to state the individual is not permitted to consume alcohol or be intoxicated outside of their residence. One participant stated this is “a new thing that I’ve started to see...and perhaps a step in the right direction.” This is encouraging as it indicates some recognition that these conditions are an unrealistic condition for individuals with FASD and secondary issues such as alcohol dependency. One participant stated that “these conditions don’t seem to actually work for deterrence.”

An interesting finding emerged with two participants who explained that while individuals with FASD are commonly breached for drinking alcohol in violation of court conditions, they have not seen their clients receive breaches for failing to complete or attend court-ordered programming or counselling. This may indicate a practice of criminalizing addiction issues, but not reprimanding non-compliance in programming intended to address the core of the problem (e.g., substance dependency; histories of trauma). Participants indicated that there should be an incentivized type of program to encourage all individuals (with and without FASD) to attend programs and counselling as part of their court conditions.

Meanwhile, Jake expressed the lack of understanding of FASD across all areas of the criminal justice system.

With someone with sort of reduced capacity, I always have issues of understanding and consent, and that is certainly a challenge in the field, I don’t think that’s only Legal Aid, I think that’s something you would see, I mean, with police officers with someone who they don’t recognize as maybe on the spectrum. There is simply not enough [education], we don’t talk about it enough, there isn’t training for it, and that’s not only me, that’s the police, the Crown attorneys, the prison staff where unfortunately most end up.

Again, discussion returned to the lack of education about how and to what extent professionals required knowledge of FASD. Evan posits that many individuals he represents who are repeatedly involved in the criminal system, have some form(s) of cognitive delay; impulse

control issue; mental health or addiction issue. Thus, FASD falls within this umbrella but is amongst multiple other forms of challenges that may require consideration in criminal matters. Evan states that in these types of situations, there is a boundary between what is a lawyer's role and what is that of another professional:

Our role is not counselling, or provision of services...lawyers have to stick to their function... We can be an investigator into their [a client's] health records, that can be very relevant...but it's not my task, in the ordinary course of events, to find housing for somebody [client].

Regardless of lawyers' choices to intervene in the matter of better supporting the individual in the community, the challenges of individuals with FASD who are justice-involved seem to occur in the community and in custody. Emily reported two central and apparent challenges encountered by individuals with FASD who are serving custodial sentences. The first was their struggle to understand and remember the multitude of rules. According to Emily, this commonly resulted in many "silly infractions" against the individuals; further, it also has implications for the individual's understanding of the environment in which live, e.g., they cannot remember that medication is dispensed at a particular time of day. The other observable issue is concerning interactions between individuals with FASD and other prisoners who may easily manipulate them:

They're just very easy to manipulate oftentimes, so they will have issues getting charges for bringing things in, or for trying to smuggle something from this unit to that unit. Stuff that they will very happily tell you later, "well so and so told me to do it".

When asked if prisoners may intentionally target individuals who appear naïve or easily led, even if other prisoners do not know the individual has an FASD diagnosis, Emily stated:

Absolutely, there is no question. They've [the prisoners] also received presentations on FASD and there might be other people in your midst that have these issues, so a lot of them are quite aware of that. Some are quite respectful of it and understand, they'll be a little more tolerant of people [with FASD], but some of them will use it to their benefit.

Participants spoke of the additional challenges faced through each step of the justice system for individuals with FASD. Upon release from custody, for example, housing options can be disrupted. One participant explained that some clients with FASD do not have a social insurance number and are therefore ineligible to apply for income support. Other clients may have “burned a lot of bridges,” owing to possible past crimes against other residents in their housing arrange, and have nowhere to live, which is commonly compounded by little to no employment history. Such challenges can compound stigma and opportunities for intervention upon release into the community (i.e., income support to provide themselves with basic necessities, fewer opportunities to benefit from community programs and supports).

Re-defining success through social supports.

My research findings suggest there are seemingly insurmountable personal and systematic challenges for individuals with FASD and their families. It can be difficult to imagine achieving “success” in this context. The “what works” literature (see Caterick & Curran, 2014; Malbin, 2002) about FASD focuses on adjusting expectations, aiming for interdependence rather than expecting full independence in adulthood, and focusing on strengths. Therefore, it was important to explore what success “looks like” for professionals who do FASD work and for the clients or patients with whom they interact. William regarded success as families learning about FASD and working together to obtain resources with the intention of educating others in the process. Olivia expressed similar sentiments about families when she stated:

Success is seeing a kid thrive, when we can fit school for the kid and not fit the kid for school “that’s when you get the win, when parents look at you and say, “oh my goodness,

thank you, it makes sense now, we're going to do this, we're going to change this, because we understand now".

The central point in this comment was adjusting the environment for the individual with FASD, rather than expecting the individual to adjust to a rigid environment. The act of adjusting the environment, can in itself, act as a form of support, particularly when issues of stigma are also being addressed. Two other professionals interviewed who have seen success among individuals in the supportive housing units in Happy Valley–Goose Bay shared a similar sentiment. Some of whom have been successful to date in avoiding further justice system involvement, one participant stated, "that's really the only thing that seems to work for these guys." Supportive housing units such as these can provide varying levels of independent living and the necessary levels of support. Individuals can receive day-to-day assistance with tasks such as submitting government paperwork, making doctor's appointments, providing transportation to appointments and grocery shopping, along with helping individuals cook. Based on participants' recounting, such simple forms of support appear to provide enough stability that some of their clients with FASD have not faced additional criminal charges.

Other participants explained that their professional success comes from being able to carefully explain the legal process to their client and working to achieve the best outcome possible for their client while being able to advocate for them if possible. Susan stated that access to programming in custody and altering the conditions imposed on individuals with FASD to take into account their disability and secondary issues could benefit not only the client but also reduced the time spent in court dealing with voluminous breach of condition matters. Another participant explained that success could also mean being able to connect the client with some form of employment, even if it is temporary. Jake and Emily both explained empathic and less

adversarial approaches to addressing the complex needs of clients are required to achieve meaningful success.

Thematic Findings – Case Studies and Interviews

Themes arising from the case studies in this research largely corresponded with patterns revealed in the interviews, with some exceptions. Interview participants spoke of shared histories of abuse, neglect, and trauma amongst their clients and patients with FASD. This too was evident in Dr. Rosales' files recounting multiple documented incidents of abuse, neglect, and trauma dating back to Alex, Logan, and Quinn's childhoods. All three individuals had experienced various forms of loss or trauma, coupled with residential instability. One interview participant, Emily, explained that many clients have "a real history of abuse and neglect, that seems to be quite prominent as well, not a stable childhood, often many have been in care." Again, FASD was discussed as being a "layer" of issues that impact their clients. Olivia stated:

FASD may be one layer of the many layers of their life, right. So, they've experienced so many losses... the challenge is trying to figure out how FASD fits into this realm of their life, and what is FASD and what is trauma?

A notable difference between the case studies and interview participants' reporting of their clients' life experiences was the role of informal supports, particularly of biological family members. Multiple interview participants spoke of their clients' ties to their biological family, regardless of whether professionals would deem such relationships as "healthy," this connection appeared to remain, even after spending various periods of time in care, away from their families.

While Dr. Rosales removed any reference to the ethnicity of the individuals in the case studies as part of the anonymization process, the role informal supports discussed in the case

studies generally differed from the interview findings. This could be the result of Alex being made a permanent ward of the province around age three, meaning they would not have been returned to their biological families, and as they matured, they likely had few memories of their biological family. For Quinn, the full impact of being removed from their mother Sylvia as an adolescent was unknown. There was a brief mention of Quinn naming their siblings while attending an assessment with Dr. Rosales; however, it is unknown how much, if any, contact Quinn maintained with their biological mother or any other biological family members after being placed in care. It is important however to acknowledge that this may be an artifact of the use of secondary data, as Dr. Rosales may not have explored the area of informal supports in detail with the patients he assisted. Alternately, Dr. Rosales' patients may not have fully disclosed the extent of their familial relationships during their appointments.

The case studies referred to Alex's tendency to be manipulated and commit crimes because their friends directed them to do so. Several interview participants also mentioned friendship and stated they were unsure of the extent of friendships that their clients or patients had with others. Emily explained that generally, her clients with FASD have "burned a lot of bridges, may not have somewhere to go [to live]". Therefore, the client with FASD may not be able to rely on the friendships they have to provide informal support as replacement of lacking formal supports. Emily further stated:

A lot of the individuals that I see, their friendships are unhealthy and they commit crimes together or they drink together, so it [the friendship] tends to matter to them, but it doesn't tend to be good for them.

Emily explains that, while a professional involved may not view the friendships in place as 'healthy' or prosocial, they still appear to be meaningful to her clients with FASD. This may be

unsurprising given the loss and hardships these individuals may have experienced up to this point.

The case studies and interviews both definitively identified the need for additional and diverse forms of support for individuals impacted by FASD, further, that such forms of support are required across the lifespan. Evan stated that within his clientele “the ones who are engaged in criminality, tend to be people who are not well looked after by the state or family, there is nowhere for them to be here.” Evan further articulated that in many (especially rural) areas of the province, there are no groups or assisted living homes or homeless shelters. He stated that in these areas, it is the individuals who are cared for by their families who tend not to get in trouble [with the law]. Despite participants identifying the need for additional supports, no professionals stated that provincial responses were sufficiently meeting the needs of individuals impacted by FASD, particularly those who are justice involved and lack informal supports that could provide supervision, teach life skills (e.g., cooking), and supply transportation.

Conclusion.

By expounding these findings, I sought to represent the experiences of individuals with FASD through the case studies obtained from Dr. Rosales’ summary case reports and the experiences and impressions of professionals from both health and justice fields who work in various capacities with individuals with FASD. Overall, the discussion within the case studies and the experiences of the participants illuminate the numerous mechanisms of support and intervention required to support individuals and their families, beginning prenatally and continuing into adulthood. In examining these experiences, it becomes evident that formal responses for support are overall lacking in NL. Further, in cases where families and informal

support networks do not have the capacity to provide sufficient support to the individual with FASD, the combined shortage of support (formal and informal) indicates additional challenges and compounding of already difficult circumstances are likely. In the following chapter, I will discuss the meaning that these findings may provide for prevention, diagnosis and intervention support efforts across the province.

CHAPTER 5

DISCUSSION

In my thesis, I aimed to uncover various forms of support and discuss which forms of formal and informal supports have (or have not) had an impact on the lives of individuals with FASD who were also justice-involved. The purpose was to identify need areas that could be improved to better support individuals early in their lives, through adolescence, and into adulthood. Thus, my focus has remained on professionals' perspectives for support needs throughout the lifetimes of individuals with FASD. My central conclusion upon analyzing the findings (as presented in Chapter 4) was the perceptible need for increased formal responses and supports for individuals with FASD throughout early development and across the lifespan; this could, in turn, lead to the implementation and strengthening of informal support networks. Formal responses should include increased prevention, diagnosis, and intervention efforts that are tailored to the individual's age. In this chapter, I discuss developmental theory, specifically the pathway put forward by Corrado and Freedman (2011) to present various points at which formal and informal supports can be strengthened based on areas of need for individuals with a diagnosis of FASD as a way to address potentially negative outcomes such as justice involvement. Also, I examine the role of stigma in themes arising from this research. I intend for this research to advance understanding of professionals' views of formal and informal support opportunities for individuals and families impacted by FASD in NL, particularly those who have become justice-involved. I commence this chapter by discussing formal support responses, their link to diagnosis, and the strengthening of informal support networks. Then, I consider the prevention and education needs of the general public, and healthcare providers and

other professionals who work directly with pregnant women and individuals potentially impacted by FASD. Next, I discuss how these issues relate to Corrado and Freedman's (2011) developmental pathway and Goffman's (1963) work on stigma. This discussion is followed by a revised pathway, illustrating risk factors diagnosis, and opportunities for supportive interventions. Finally, I address the current circular issues at play within NL's response to FASD and discuss implications and future directions of this research.

Response of formal supports and improving informal support opportunities

Themes within this research overwhelmingly illustrate the inadequacy of formal supports available for individuals with FASD and their families in NL; a topic that repeatedly emerged in the case studies and from the interviews. The inadequate formal responses, therefore, do not only impact individuals at specific points in time, nor is it an issue only faced by individuals who have FASD and are already justice-involved. Rather, gaps in formal responses in the manner of screening of pregnant women and support for those impacted by FASD appear lacking for the duration of their lives. This holds true particularly when informal supports, such as familial relationships, have broken down or families do not have the capacity (financially or otherwise) to provide ongoing wraparound supports.

Access to proper FASD assessment and diagnosis through a multi-disciplinary team approach is a crucially important step towards improved identification and thus increase the visibility of FASD within NL. This was evident in the interview findings as participants described "the aha moment" in which parents and caregivers became aware of their child's FASD diagnosis and reported to professionals involved the relief of FASD explaining some of their child's challenges. A diagnosis as a stand-alone point of intervention or formal support is

likely not sufficient in the long-term, as parents will eventually (or immediately) require support and knowledgeable individuals who can provide information and/or intervention options to address challenges. Further, navigating decisions about disclosure of the diagnosis and coping with possible stigmatizing reactions are additional challenges in which support is helpful.

Various diagnostic models could be implemented to meet the needs of both rural and urban areas as evinced by the Labrador Grenfell Health team and other diagnostic approaches (Ens, et al., 2010).

Details surrounding the circumstances of siblings were lacking within the summary case reports. All three individuals had either lost (or did not ever have) contact with most or all of their siblings. I also probed this topic with interview participants, who mentioned their clients' attempts to maintain contact with their informal support networks including parents and siblings. Efforts to preserve relationships between siblings, even when in foster or adoptive settings, should be considered, as informal bonds can be important forms of intervention and support. Further, the sharing of information regarding diagnosis of FASD in one sibling with caregivers of siblings may provide the information needed to seek an assessment for their child, thereby offering an intervention point earlier in their development. In this sense, FASD diagnosis can provide meaningful, long-term support when it is an entry point to additional forms of support and resources. Early diagnosis and intervention is a proven protective factor (Bertrand, 2009; Paley & O'Connor, 2009; Streissguth et al., 1997). As expected, receiving a diagnosis as adults and as teenagers was likely a contributing factor to some of the challenges experienced by Alex, Logan, and Quinn, as well as their biological and foster families and professionals involved in their lives.

The diagnoses received later in life would have presented fewer opportunities to implement accommodations in caregivers, education and social interactions earlier in life, thereby potentially having a protective effect. Critical intervention points, such as those discussed in Corrado and Freedman's (2011) pathway, would have been missed. Therefore, FASD diagnosis as entry or pathway to access FASD informed healthcare providers, educational and employment supports; support in the home when required, and options for assisted living in adulthood has the opportunity to strengthen formal support responses provincially. As evident in the cases of Alex, Logan, and Quinn, this has not always been the case. For example, in Logan's case, no long-term formal supports were noted once they were released from the hospital and returned home. This could be as a result of there not being any ongoing formal supports in their community/region, or from a lack of communication between health and social professionals in the matter. Importantly, the role of stigma in the absence of formal supports cannot be overlooked, as stigmatized ideas about FASD and its causes may contribute to this circumstance. Bolstered formal supports could provide opportunities for families to become FASD informed. In addition to access other caregivers for peer support and potentially reduce caregiver burnout as a result of long-term overtaxing of the burdens of raising individuals with FASD without support (Olson et al., 2009).

Interview findings also indicate that professionals' identify improved formal support responses for justice-involved individuals with FASD are required. The confirmed diagnosis of FASD was illustrated by participants to be an important factor when accounting for the entirety of an individual's circumstances during legal proceedings, in custody, and upon release into the community. Again, an FASD diagnosis in this context may be most helpful when it provides a pathway for professionals to identify the risk/need factors of each individual. Additionally,

formal confirmation of a diagnosis can act as a mechanism to provide professionals involved (e.g., lawyers, judges, prison staff, probation officers, housing support workers) with knowledge about how to support the individual at all points of interaction with the justice system. Ideally, adequately supporting individuals would result in continued desistance from crime; however, it is not a realistic view to expect this result for all (Blumstein, Farrington, & Moitra, 1985). Importantly, these issues are not unique to individuals with FASD, rather, the cyclical nature of administrative breaches, types of crimes committed, unstable housing, employment and substance use, are common amongst justice populations more generally (Office of Correctional Investigator, 2017; Giordano, Cernkovich, & Rudolph, 2002). However, for justice-involved individuals with FASD, the processes of understanding their actions, the subsequent consequences, and desisting from crime are compounded (Fast & Conry, 2009). For some, these navigating poverty and socio-economic wellbeing may also be a pressing issue (Flannigan et al., 2018). Regardless, efforts are required to address the cyclical patterns such as that of numerous breaches for substance use amongst a population with an identified form of permanent brain damage and likely coupled with impulsive and trauma-based reactions. At the root of the ability to both address and change current responses is to provide targeted FASD training to professionals, allowing them to become FASD informed. Further, it illustrates the need for a deeper understanding of ongoing criminalization of some symptoms of FASD. Despite these recognized areas of need, individuals' agency should also be considered; not all individuals diagnosed, or their caregivers will want or accept supports. However, access and ability to choose the involvement of formal supports and to what degree are paramount. I also argue that public education and awareness campaigns about alcohol and pregnancy are necessary to address prevention and screening efforts.

Becoming informed: Educating a population and its professionals

Participants' responses demonstrated an overall need for education about the topics discussed in this research, namely alcohol use and pregnancy, the impact and effects of FASD generally and FASD in justice settings. Health professionals interviewed reported a need to increase screening of all pregnant women in the province for alcohol use. However, such screening efforts require careful and thoughtful development and implementation to mitigate bias and screening of specific populations and not others. Further that women who were habitual alcohol consumers during pregnancy as laid out in the 2016 updated Canadian Diagnostic Standards (Cook et al., 2016) require referral for follow up by healthcare providers and the provincial Perinatal Program. Doing so would also provide a clearer picture and accuracy of reporting across the province. Participants also explained that screening should be implemented in combination with additional education about building trust and asking women questions without stigmatizing them. There was a general sense of from all participants that the provincial response to FASD is so inadequate that current FASD work "is barely scratching the surface." I, therefore, recommend that a multi-faceted approach is needed to fully address two distinct areas of need: prevention and intervention, both of which must apply a stigma lens. Intervention needs refer to individuals currently living with FASD but undiagnosed, living with an FASD diagnosis and no support, and the need for support amongst families and caregivers of individuals with FASD, and supportive living arrangements for youth and adults with FASD. Intervention needs also require addressing the involvement of individuals with FASD in the criminal justice system. This necessitates FASD diagnostic teams able to assess the province's island population, outside of the Labrador Grenfell Health Authority, and individuals who may be part of a forensic

population. Thereby providing access to FASD assessment for all, regardless of age, life history or the presence of a stigmatized label (e.g., criminal).

Participants reported being largely self-taught about FASD through a variety of mechanisms including online journals, webinars, conferences, and FASD training offered within the province. However, participants all expressed that their colleagues, and the public in general, required more education about FASD and/or the risks of alcohol and pregnancy. All of the participants acknowledged or discussed in various ways the complexities of addressing FASD within health and justice systems in the province. Further, additional customized FASD training for professionals who commonly encounter individuals impacted by FASD (e.g., teachers; social workers; child support workers, professionals in all three aspects of the justice system: court, custody and community release) is essential.

Prevention needs refer to screening and prevention efforts for all pregnant women by care providers and are required province-wide. Such efforts should also assume a harm-reduction and non-punitive approach, aiming to address women's fear of losing (access to or custody of) their child. Public-based awareness campaigns require messaging beyond not mixing alcohol and pregnancy; instead, they also require directly speaking to the public's preconceived ideas and stigma related to who drinks during pregnancy. Additionally, this approach requires a cultural lens and focus on breaking stereotypes and racist ideas of FASD as an "Aboriginal issue." Evidence-based messaging can dispel myths, more generally, about alcohol use and FASD, thereby countering some of the stigma that has often been associated with each. Public awareness campaigns, public health messaging, communities and partners support of women all play important roles in such prevention efforts (Corrigan et al., 2018; Drabble et al., 2011; Poole, 2008).

Opportunities for intervention: Revisiting developmental theory and stigma

Developmental theories' attention to the family, i.e., attachment to the family, monitoring, and consistent discipline (Laub & Sampson, 2003), and risk factors such as maternal consumption of alcohol (Domburgh et al., 2009) are useful in the theoretical understanding of this research's findings. This was reflected in the findings through residential instability, low levels of attachment to family and friends, and diagnosis of FASD. The developmental pathway of Corrado and Freedman (2011) serves as a focal point within this thesis as it directly incorporates prenatal risk factors (discussed within their work as alcohol), to possible justice system involvement. This pathway takes into account various and compounding effects of risk factors that may occur throughout development. Corrado and Freedman's (2011) pathway is not a linear trajectory, nor (like Sampson & Laub, 1993) are they contending that the trajectory cannot be altered. Instead, for each risk factor identified, there is a corresponding intervention point. Within the present research, the case studies and interview participants reported all of the risk factors discussed in Corrado and Freedman's (2011) pathway in various contexts, i.e., multiple foster care placements, early school failure, early substance use, aggressive/risk-taking behavior. The findings also revealed multiple forms of loss and trauma as a result of residential instability, removal from biological families, as well as foster families in childhood and adolescence. By applying a developmental lens to these experiences, combined with a strength-based approach that draws on individuals' strengths, developmentally appropriate supports can result in success and resilience for individuals with FASD (Knorr & McIntyre, 2016). The importance of early diagnosis, intervention, and supports therefore should not be minimized.

Corrado and Freedman's (2011) pathway holds true within this research; however, the role of early diagnosis and interventions should be considered, particularly in the forms of support for parents and caregivers, supportive strategies within the home and school environments, observation of life skills and positive behaviour modeling via supported caregivers/parents, and supportive living interventions. I propose a new consideration of Corrado and Freedman (2011)'s developmental pathway, which explicitly demarcates FASD as the prenatal risk factor and includes the role of formal and informal supports; this is illustrated in Figure 2.

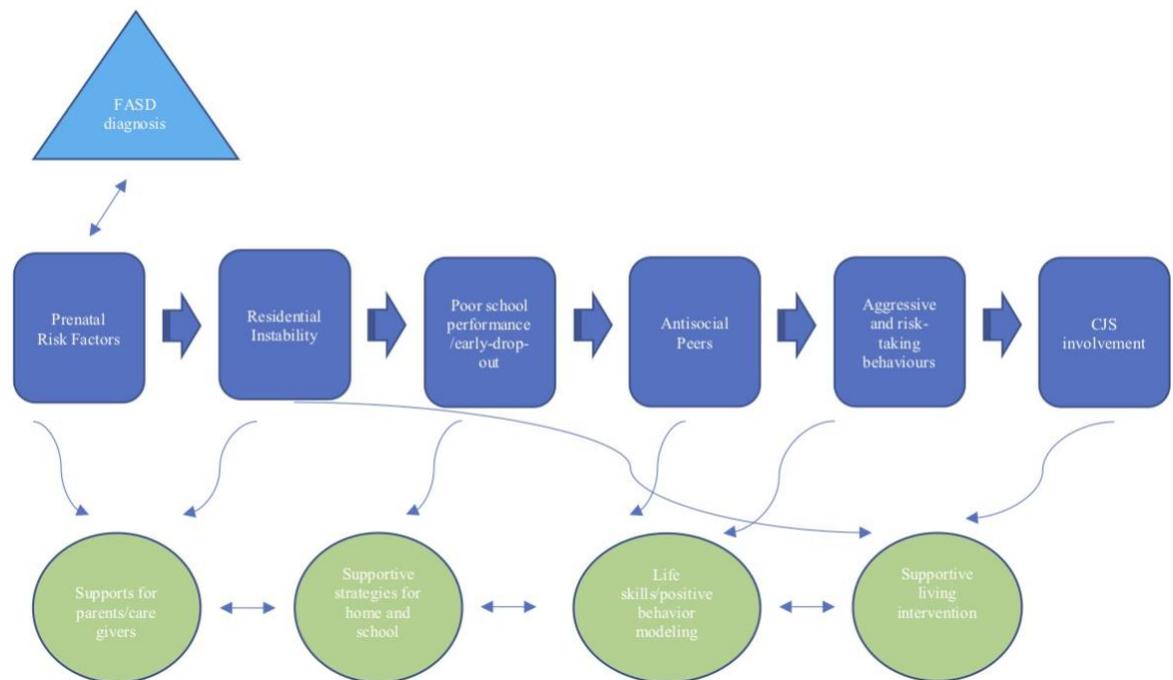


Figure 2: Revised pathway: Prenatal risk factors, diagnosis, and opportunities for supportive interventions.

A diagnosis of FASD serves as an important factor within this revised pathway, in which it can act as a pathway to additional supports, and provision of supportive environments. I suggest that further work is required to understand the role of residential instability in individuals

with FASD (see Rock et al., 2015), and what type of residential living arrangement(s) most effectively promote protective factors for children and youth are removed from their homes. Such work should apply a critical lens to understand the role of removal from biological families as a possible form of trauma, particularly when the removal is not “endorsed” by the child or adolescent involved (Wechsler-Zimring, Kearney, Kaur, & Day, 2012). This more refined pathway recognizes that caregivers/parents who are supported in their parenting of individuals with FASD can act as a supportive intervention.

Finally, the pathway outlined in Figure 2 and based on this thesis’ results proposes an imagination into life *after* the proposed pathway by Corrado and Freedman (2011), which “ends” with criminal justice system involvement. I theorize that effective interventions before and after criminal justice involvement can result in periods of, or prolonged desistance from crime. Participants reported that the model currently implemented by the Nunatsiavut Government¹⁷ in the form of supportive living units with levels of support based on individuals’ needs has resulted in previously unseen success and desistance. Therefore, I propose that the use of such supportive living units require additional consideration as a preventative intervention for individuals with and without risk factors as laid out in Corrado and Freedman’s (2011) work. Opportunities to access supportive living environments should also be available to individuals who do not have justice involvement, but require higher levels of support may not yet have “arrived” at criminal justice involvement, thereby, acting as an added protective factor.

I return now to Goffman’s (1963) theory of stigma in recognition that opportunities for assessment, interventions, and support can all be impacted by the role of stigma. Further, that

¹⁷ Other organizations in Newfoundland and Labrador and elsewhere offer similar supportive housing services for individuals who are justice-involved and/or have mental health challenges. For the purposes of this research, the model implemented under the Nunatsiavut Government has been highlighted as a result of participants reporting of their clients’ success through the service.

the effects of stigma and development of a “master status” can be profound, and long lasting for individuals with FASD, in addition to their parents and caregivers. As Bell et al. (2016) discuss, stigma can act as an additional barrier in choosing whether to disclose alcohol use, accessing support, and deciding whether to disclose a diagnosis. Participants discussed stigma at length and in various contexts throughout the interviews. In their professional roles, participants discussed encountering stigmatizing reactions regarding “who” drinks during pregnancy, reasons why women do not disclose substance use to their health providers, and their clients’ complex histories of trauma and stigma. Within the case studies, stigma was not explicitly discussed, although it was clear that Alex, Quinn, and Logan, and their families, faced adversity and exclusion throughout their lives. Quinn’s mother, Sylvia spoke candidly with Dr. Rosales about her life, raising Quinn, and her use of alcohol during pregnancy. Sylvia was also open to Dr. Rosales about communicating with her former foster parents. It is difficult to know with certainty what specific factors led to Sylvia’s openness in discussions with Dr. Rosales. I suggest that it may be the result of Dr. Rosales’ non-judgmental approach and a feeling of “safety;” given the amount of time that had passed, it was a historical disclosure. Quinn was an adult, and Sylvie’s decision to disclose would likely not have been impacted by the fear of losing contact with her child.

Although this specific case was promising in this regard, the effects of stigma continue to contribute to how individuals impacted directly or indirectly by FASD navigate their daily lives. In attempting to address issues of access to diagnosis, early interventions, and support, it is essential to consider the possibility of stigma, shame, and guilt at each stage. Further, efforts to address better supporting individuals impacted by FASD and their families requires navigating

the tension between the benefits of supportive interventions and possible stigmatization, blame, and labelling.

What it all means: Policy Implications in Newfoundland and Labrador

The findings of this research indicated that addressing prevention and intervention efforts for FASD is within the province's best interests, in addition to the best interests of individuals impacted directly and indirectly by FASD. The findings also indicated that circular issues exist, including an underreporting by care providers of alcohol use during pregnancy, a reduced ability to screen all pregnant women in the St. John's region where approximately 60 percent of the province's live births occur (Perinatal Program Newfoundland and Labrador, 2013), and a gap in public awareness through large-scale awareness based messaging, which all propagate one another. Within intervention efforts, additional interrelated issues continue to occur.

Contributing to this is the absence of assessment and diagnostic work taking place on the island portion of the province (excluding St. Anthony), where just over 90 percent of the province's population resides (Statistics Canada, 2016). Further, since Dr. Rosales' retirement in 2015, adult populations across the entire province lack access or referral options to FASD assessments, including adults in custodial or institutional environments. As a result, there are unknown or unclear referral pathways for physicians and other professionals (e.g., social workers) seeking an FASD assessment in three out of four of NL's health regions. Thus, without assessment and diagnostic options for healthcare providers and social workers, opportunities for early intervention and early provision of support to the impacted child and their caregivers are limited (Paley & O'Connor, 2009; Watson et al., 2013). The limited amount of FASD specialists and specific formal and informal intervention options results in professionals and caregivers

attempting to address individuals' needs with a piecemeal approach. Missed opportunities for early intervention may be related to the development of additional risk factors as laid out in Corrado and Freedman's (2011) pathway; this was certainly exemplified with the case studies of Alex and Logan who were either referred for early assessments or were hospitalized for early substance use in childhood. Yet, FASD diagnosis in itself is not sufficient as a form of support, rather, the permanence of the disorder and its multiple impacts are further markers for which require additional supports.

The importance of confirmed diagnosis for justice-involved individuals was identified as an issue in NL as early as 2008 (Safer & Boland, 2008). Yet, efforts in this area have largely been slow-moving, except for the FASD diagnostic team in Happy Valley-Goose Bay and St. Anthony, and other FASD work across the province conducted predominantly by the fasdNL Network and regional committees. Coupled with the absence of professionals diagnosing adult populations in the province, this remains one of the many barriers facing both individuals with FASD and the professionals who interact with them. The findings in this thesis indicate that these critical issues remain.

Among the most evident implications to emerge from this research was the success witnessed by professionals whose clients accessed supportive housing units. One participant stated that this approach was the only type of intervention that they have witnessed that has had any prolonged success. Likewise, in his summary case reports, Dr. Rosales made the same recommendations when addressing the future needs of the individuals in the reports. In certain individual cases, such as that of Quinn, Dr. Rosales stated that Quinn's combined level of impairment coupled with forty plus years in adverse environments was so significant, that they were unable to function without a highly supervised and supported living arrangement. I argue

that this approach be more widely accessible – throughout various rural and urban areas, with eligibility criteria, and age of entry to supportive living options. The provision of such services should provide affordable housing options to individuals with complex needs such as FASD who may require such support earlier in life during the transition into adulthood as a preventative measure and not reserved only for individuals who have justice or institutional histories. Further, supportive living units available throughout rural and urban areas of the province should provide options for individuals to be close to their home communities if they choose, and therefore closer to the informal supports they may already have, without placing the responsibility of high supervision on the informal supports themselves. Doing so could provide opportunities to maintain or strengthen familial ties – a connection that one participant noted appeared stronger amongst Indigenous clients than non-Indigenous. However, it is difficult to reconcile that only adult populations require supportive living environments (see Tait et al., 2017).

Therefore, I put forward that in-home support (i.e., respite) should be available across the province earlier in the lifespan, throughout childhood and adolescence to address issues of caregiver burnout and stress (Olson et al., 2009). This approach could provide ongoing levels of supervision, thereby helping to maintain the three mechanisms Laub and Sampson's (2003) work: attachment to the family, monitoring, and consistent discipline. Further, the introduction of such forms of support in the caregivers' home may create a smoother transition to supportive living units in adulthood (Coons et al., 2016; Watson et al., 2013). However, implementing such an approach would require the removal of the eligibility qualifier of an IQ of 70 or below currently in place in the province. Thus, a final recommendation stemming from this research is to follow other provinces such as Quebec (see Services Québec, 2018) and remove this archaic eligibility criterion. Ultimately, these approaches require changes to prioritization of FASD,

formal support options for individuals with complex needs such as FASD, and a shift toward the use of formal supports to aid in upholding informal forms of support.

Providing support for individuals with FASD and their families requires various factors such as diagnosis and follow up care, formal supports following diagnosis, and strengthened facilitation of informal supports (e.g., maintaining sibling relationships; accessing peer support groups). Therefore, strategies to address these issues should centre on a non-stigmatizing and coordinated approach. Similar to the levels of prevention efforts as discussed by Poole (2003, 2008), I propose four levels of intervention to prioritize response to FASD interventions and summarize the discussion above and include: access to early life assessment, diagnosis and follow up, education for professionals in various sectors (health, justice, education, social, and community). These interventions would be accompanied by formal support offerings for caregivers and parents of individuals with FASD (e.g., respite care, FASD specialists), and supportive living interventions accessible for individuals who have been justice-involved. Such interventions should also be available to individuals who have not been justice-involved but require supportive living options, especially upon transition to adulthood.

The proposed interventions may target different individuals or populations at varying points in time. However, they are interconnected and encompass a goal of improving outcomes for individuals and families impacted by FASD. Finally, each area of intervention requires careful consideration of non-stigmatizing approaches and the strengths of offering supportive interventions at various life stages.

Limitations

The case reports used in this research are a form of secondary data, that is, information that was collected for alternative purposes (e.g., reports prepared for court). As a result, some limitations exist. It is important to appreciate that the cases discussed are unique, and provide insights into the lives of three individuals, largely shaped by what has been documented about them by others. Some limited or extraneous details were available in the case reports, or events may be referred to without a full contextual or sequential understanding. Given the personal nature of the information, it is possible that full disclosure may not have been given to the professionals compiling their files. The sample of cases available and selected for this research was limited to individuals for whom Dr. Rosales received referrals, and then assessed and diagnosed with FASD. Other cases involving undiagnosed or misdiagnosed FASD in individuals who are criminally involved were not included in this sample. The three reports examined as case studies within this research were chosen because they were descriptive of many factors examined within this research (e.g., caregiver circumstances). Dr. Rosales authored other reports which may have lacked contact with biological or foster family members or may not have been successful in obtaining complete medical, social or educational records.

The interviews in this research provide insight into health and justice professionals' insights and experiences working with individuals with FASD. However, these interviews capture a sample of some professionals' experiences and may not reflect the experiences of all professionals who have worked and continue to work with individuals with FASD in the province. Further, the experiences of the professionals may be impacted by the region in which they worked, and the period in which they worked most closely with individuals with FASD.

Obtaining interviews with professionals had some shortcomings. Some participants may have been unable to respond to my request for an interview due to limited schedules; junior

professionals without experiences with clients with FASD, or they may have lacked interest in the research topic. Some participants may have had additional clients who had undiagnosed FASD, and this may have affected their responses. Additionally, the specificity of this research topic within NL as a setting created a narrow area which may have played a role in the response of potential participants.

The restricted geographical location of this research to the province of NL is a minor limitation of this research. Given the small pre-existing body of literature relating to FASD and non-existent literature on FASD and the justice system in the province, this work has strong applicability for professionals working in the criminal justice system and those working with individuals with FASD, particularly within NL. However, this applicability contains a caveat; that is to say, these case studies should be taken seriously and examined as such, yet they are not representative of all individuals with FASD, nor are they indicative of all individuals with FASD who are justice-involved. Despite these limitations, this work fills a critical gap of information about the link between a medical diagnosis of FASD and the justice system and provides context about the response to these issues in NL.

The sample size of interview participants and case studies in this research could be viewed by some definition as low. Both qualitative and quantitative research can at times, lean towards recognizing and appreciating larger sample sizes (Maruna & Matravers, 2007). While gaining additional perspectives regarding FASD and support would be worthwhile for future research, I argue that the specific nature of this research and the case studies offer insight and detail at an individual report level. It is my hope that this research contributes to a greater understanding of the complexities and experiences of persons (Gadd & Jefferson, 2007) impacted by FASD and FASD work more generally in NL.

Finally, I have remained aware and careful of my personal bias within this work, as I am impacted by the work that I do and the population I work with, and naturally, of my own family's experiences. This bias has been carefully considered throughout the research process. I have followed what the data in this project has shown me and not allowed my previous knowledge of FASD or social supports (available or lacking) in NL to cloud the findings, direction or discussion of this research. However, my experience and prior knowledge have inevitably impacted my findings, so this was balanced by an ongoing reflexive approach (i.e., reflecting on my own prior knowledge, experiences, and bias) to the work. Efforts to address bias within this research were mitigated by interviewing participants from varying regions and professions accompanied by a range of experiences of working with individuals with FASD. In doing so, different sides of the issues at play were discussed and highlighted.

Future Directions

This research is an initial step in providing research about justice-involved individuals with FASD in NL and contributes to the small existing body of literature about FASD more generally in the province. It would be beneficial to expand this research by focusing on a more extensive and diverse sample of professionals, from each region of the province, and other professions, including judges and probation officers. In addition, future work examining forms of support would also include perspectives from social workers and caregivers directly.

Other possible future research could examine the role of disclosure of substances during pregnancy and health and social systems reactions to such disclosures. Alex, Quinn, and Logan's cases noted that they were all removed from their biological families at various points in their lives. How documentation discusses substance use and/or how self-reporting data of

substance use during pregnancy is used are of interest, particularly in how it impacts child protection, and child custody issues.

I also suggest that longitudinal research is conducted to examine justice involvement of individuals with FASD from a variety of caregiver environments including biological, foster, adoptive families to examine if there are relationships between the type of primary care environment and later justice involvement. I also recognize that research about FASD more generally within the province, which aims to reduce stigma and further explore the challenges and successes of individuals impacted by FASD is indispensable.

CHAPTER 6

CONCLUSION

To conclude, I revisit my original research question: *How do professionals' view risk and protective factors, access to diagnosis and supports? In their view, what factors impact the experiences and outcomes for individuals with FASD who are also justice involved?* FASD is a complex condition that can affect individuals in profound ways at each stage of their development. My findings reveal that the intricate and interrelated issues of stigma, underreporting by care providers, and women using alcohol during pregnancy all impact the visibility of FASD in NL. When FASD does occur and is left undiagnosed, individuals impacted by it may face additional issues as a result of FASD symptoms, compounded by a lack of understanding of the complex condition, appropriate strategies to diagnose it, and critical supports to assist individuals/groups at each developmental life stage. Cases of FASD can be overlooked as a result of bias or misunderstanding of who may have FASD or how FASD affects individuals differently. Therefore, recognition of the disorder is an important first step to begin assessment, diagnosis, and implementation of supports.

FASD diagnosis alone, however, is not sufficient to provide meaningful long-term support. Instead, it should act as a pathway to additional forms of ongoing support for individuals diagnosed and their caregivers. I proposed a revised developmental, FASD-specific pathway, expanding the work of Corrado and Freedman (2011) to illustrate the role of various supports and their ability to address known risk factors for antisocial behaviour and justice involvement. In this model, I propose four levels of intervention: access to early life assessment, diagnosis, and follow up; education for professionals in various sectors; formal support offerings

for caregivers and parents of individuals with FASD; and supportive living interventions accessible for all individuals who may or may not be justice-involved. A combined approach of management strategies for FASD may include educational resources for caregivers and educators; medication for impulsivity or sleep issues; and accommodations in the home and educational environment; this can mitigate adverse outcomes, including justice system involvement. Some of these strategies may be borrowed from approaches to addressing mental health challenges or other forms of complex needs. However, such strategies and modified approaches may also be helpful in criminal justice settings as well, regardless of the age/developmental stage of the individual. Further, access to supportive living environments and assisted employment programs, which provide some of the strategies listed above, can be important factors in providing stability in adulthood, particularly for individuals whose relationships with informal supports have been profoundly impacted or have broken down.

This thesis importantly contributes to knowledge about professionals' experiences in attending to FASD work, its strengths, challenges, and gaps in NL. Further, it provides insights into social supports required for supportive living across the lifespan and the current shortcomings of the justice system's response to individuals with FASD in NL. This research offers valuable insight into the experiences of professionals who work with this population and a foundation to address some of the gaps identified by participants. For these reasons, this research is an important contribution for practitioners and advocates and FASD work more generally in NL. By exploring the intersections of health and justice systems, in addition to community-based efforts within the province, this research highlights persistent weaknesses, but also several strengths, of Newfoundland and Labrador's response to FASD.

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APPENDIX A

Case Reports Research Instrument

Case report number:

Assigned pseudonym:

Date of report (year):

Report authored by (name professional group):

Report written/addressed to (name professional group):

Reason for report:

Age of individual (approximate):

Information about biological parents:

Information about foster parents/adoptive parents:

Information about siblings:

Noted characteristics of home environment(s):

Note characteristics of familial/caregiver relationship(s):

Maternal history:

Paternal history:

Date of FASD diagnosis:

Noted co-morbid diagnoses:

Medication(s) history:

Medication(s) current:

School history:

Behavioural characteristics:

Alcohol and/or drug used:

Type of criminal involvement:

Health supports:

Provincial health program:

Psychiatric assessment/hospitalization:

Community supports:

Community health program:

Outreach program:

Other:

Sharing of report- who is copied:

Who requested/referred initial evaluation:

Peers/friends information:

Other notes:

APPENDIX B-1

Interview Guide: Legal Professional(s)

Katharine Dunbar Winsor
 Department of Sociology
 Memorial University of Newfoundland & Labrador

Date:

Interviewer:

Interviewee:

Location where interview was conducted:

Other Notes:

Hi, I'm Katharine. Thank you for participating in this interview. Just as a reminder, as you saw in the informed consent form which you have signed, you are welcome to end the interview at any time. Also, you are free to opt out of any questions that are part of this interview, including questions concerning demographic details. Do you have any questions for me before we begin?

1. What is your occupation? What does that entail?
2. How long have you worked in your position? What did you do prior?
3. In what capacity do you work with individuals with FASD?
4. Have you received any (specialized) education/training related specifically to FASD?
 Where does your knowledge/understanding of FASD come from?
5. How are you involved in the daily lives (or the general experiences) of individuals with FASD?
6. In your years of working as a [Private defence lawyer/Legal Aid lawyer], how many individuals have you worked with who are living with FASD? What is the frequency of interaction between you and them?
7. What are your impressions of FASD affected individuals' experiences of living in the community?
8. What forms of support (formal or informal) have you witnessed these individuals having in place?

9. What forms of support (formal or informal) have you witnessed these individuals lacking?
10. What are the most common challenges you find individuals with FASD experience once they are involved in the criminal justice system? Does this vary by age, gender, ethnicity/race, SES? Why have you highlighted these in particular? Why do you feel these challenges are present?
11. What are some challenges faced with affected individuals' access or use of social supports?
12. In your opinion, how would court proceedings be impacted if there were an increased focus on FASD throughout the court proceedings (e.g., a multi-disciplinary diagnostic team in the region, experts who could provide reports, probation and correction officers who were educated about FASD)?
13. Are you aware of changes – positive or negative – that individuals with FASD have experienced over the course of their time working in this area related to these various challenges. What led to these changes?
14. Are there existing agencies/organizations in the province that could play a more active role in FASD prevention, awareness/education, diagnosis, and/or service/program provision? Or in supporting your work with FASD? If so, could you please discuss in what ways? What do you feel is/are the possible reason(s) for this disconnect? How could these agencies/organizations be reached/“invited to the table”?
15. Are there certain professionals/services/programs that should be introduced in the province that you believe are necessary for FASD prevention, awareness/education, diagnosis, and/or service/program provision? If so, could you please discuss in what

ways? Would they assist in/contribute to your FASD-related work? What do you feel is/are the possible reason(s) why these positions/organizations do not exist? How could their introduction/implementation be facilitated?

16. Let's talk a little about successes. What does success mean/look like to you? What are a few examples of successes that you have witnessed with these individuals? What do you feel contributed to these successes?

17. Have you seen success through their access and use of social supports (e.g., programming; counselling; educational accommodations; caregiver or peer support)?

18. What changes/recommendations/education needs to take place, or is the system currently supporting these individuals sufficiently?

19. Would you like to add any final comments that you believe are important to this topic (and should be explored in [this] research)?

APPENDIX B-2**Interview Guide: Medical/Health Professional(s)**

Katharine Dunbar Winsor
Department of Sociology
Memorial University of Newfoundland & Labrador

Date:

Interviewer:

Interviewee:

Location where interview was conducted:

Other Notes:

Hi, I'm Katharine. Thank you for participating in this interview. Just as a reminder, as you saw in the informed consent form which you have signed, you are welcome to end the interview at any time. Also, you are free to opt out of any questions that are part of this interview, including questions concerning demographic details. Do you have any questions for me before we begin?

1. What is your occupation? What does that entail?
2. How long have you worked in your position? What did you do prior? For how long?
3. In what capacity does your present/most recent work and did your previous work focus on FASD?
4. Have you received any (specialized) education/training related specifically to FASD?
Where does your knowledge/understanding of FASD come from?
5. Are/how are you involved in the daily lives (or the general experiences) of individuals with FASD?
6. In your years working as a [Physician & FASD Consultant/Perinatal Health Policy Consultant], approximately how many individuals have you worked with who are living with FASD? What is the frequency of interaction with them and what does this interaction look like?
7. Could you please tell me a little bit about access to and the process of diagnosing FASD in Newfoundland and Labrador?

8. What forms of support (either for the individual and/or the family/caregivers) are available once an individual receives a diagnosis?
9. Is there assistance/guidance for the individual/caregivers to help navigate (e.g., referrals; reminders; timelines) supports and interventions?
10. What are the most common challenges you find individuals with FASD experience?
11. What are the challenges the healthcare system faces when working to address the needs of individuals with FASD?
12. What are some challenges faced with their access to or use of social supports?
13. Are you aware of changes – positive or negative – that they have experienced over the course of their time working in this area related to these various challenges. What led to these changes?
14. How do you feel the province/region would be different if a multi-disciplinary diagnostic team approach in place?
15. Are there existing agencies/organizations in the province that could play a more active role in FASD prevention, awareness/education, diagnosis, and/or service/program provision? Or in supporting your work with FASD? If so, could you please discuss in what ways? What do you feel is/are the possible reason(s) for this disconnect? How could these agencies/organizations be reached/“invited to the table”?
16. Are there certain professionals/services/programs that should be introduced in the province that you believe are necessary for FASD prevention, awareness/education, diagnosis, and/or service/program provision? If so, could you please discuss in what ways? Would they assist in/contribute to your FASD-related work? What do you feel

is/are the possible reason(s) why these positions/organizations do not exist? How could their introduction/implementation be facilitated?

17. Let's talk a little about successes. What does success mean/look like to you? What are a few examples of successes that you have witnessed in individuals with FASD? What do you feel contributed to these successes?

- a. Have you seen success as a result of their access and use of social supports (e.g., programming; counselling; educational accommodations; caregiver or peer support)?

18. Would you like to add any final comments that you believe are important to this topic (and should be explored in [this] research)?

APPENDIX C

Informed Consent

Title: The impact of social supports on experiences of justice involved individuals with fetal alcohol spectrum disorder in Newfoundland and Labrador

Researcher(s): Katharine Dunbar Winsor, Sociology Department, Memorial University
kwinsor@mun.ca

Supervisor(s): Dr. Adrienne Peters, Assistant Professor, Sociology, Memorial University,
apeters@mun.ca 709-864-2665

Dr. Rosemary Ricciardelli, Professor, Sociology, Memorial University, rricciardell@mun.ca
709-864-7446

You are invited to take part in a research project entitled *The impact of social supports on experiences of justice involved individuals with fetal alcohol spectrum disorder in Newfoundland and Labrador*¹⁸

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Katharine Dunbar Winsor, if you have any questions about the study or for more information not included here before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

As part of my graduate thesis, I am conducting research under the supervision of Dr. Adrienne Peters and Dr. Rosemary Ricciardelli exploring the impact of social supports for criminally involved individuals with fetal alcohol spectrum disorder (FASD) in Newfoundland and Labrador (NL).

Purpose of study:

The purpose of this research is to provide further understanding of the impact of social supports on outcomes for criminally involved individuals with a diagnosis of fetal alcohol spectrum disorder in NL. Further, this research will explore how social supports and interventions shape individuals lives when they live with both FASD and have past or present involvement with the

¹⁸ The title of this project changed after participants had signed the informed consent.

criminal justice system. This research will explore the relationships between health systems and diagnosis of FASD, social supports and intervention and justice system involvement within this province. In order to accomplish this research, interviews will be conducted with approximately 5 individuals who work or have worked in the FASD field.

What you will do in this study:

Participants are asked to be interviewed in person or by telephone for this study. Questions will be regarding their professional role within the lives of individuals with FASD, their observations of personal and structural barriers faced by such individuals, and discussion of how our system can improve or has improved with regards to supporting individuals across their lifespan.

Length of time:

Interviews will take approximately 45 minutes to 1 hour in a one-on-one setting.

Withdrawal from the study:

If at any point prior to, during or following the interview until the point that the research has been submitted to the supervising professors, participants may choose to withdraw from the study. Participants can withdraw either verbally or in writing and in doing may also choose to have any data collected through them omitted from the research.

Research will be submitted to Dr. Peters and Dr. Ricciardelli on June 30, 2018; following this date, research will be unable to be removed. However, withdrawal at any point prior to this date will not result in any form of consequence to the participant.

Possible benefits:

Possible benefits of being part of this study include contributing to knowledge for the purpose of giving a fuller understanding of experiences of justice-involved individuals with a diagnosis of FASD in NL. Copies of this research will be provided to participants for reference within their professional community or volunteer community.

Possible risks:

Due to the discussion of this research being centered on individuals' experiences, generally and does not aim to discuss specific individuals, this research poses minimal risk. Participants are unlikely to be adversely impacted, as the area of individuals with FASD and the experiences they face is a point of common discussion in their professional responsibilities.

Confidentiality:

In ensuring that identities of participants are accessible only to those authorized to have access, data collected and information given by participants during this research will be kept confidential and not shared with other individuals or groups. I will maintain confidentiality of your name and the contributions you have made to the extent allowed by the law. I acknowledge my responsibility to protect the confidentiality of all participants in my research study and am committed to maintaining and protecting the confidentiality of any personal information through the use of various protective measures, i.e., not disclosing information discussed to individuals

outside of the research, exclusively assuming the responsibility of transcribing audio recordings and storing these recordings and the related data files in a secure location.

Anonymity:

Participants' anonymity will be protected throughout the research process. Participants' identifying characteristics such as number of years in the profession or geographic locations worked will not be included or discussed. Every reasonable effort will be made to ensure participants anonymity, including the use of pseudonyms, and *any identifying information such as the organization or specific field s/he works in, and any specific involvement s/he has had in testifying in a prior case involving individuals with FASD will be excluded from the research. There is a still a small chance that an informed reader may be able to identify a group of professionals based on the nature of direct quotes. Participants are free to skip any questions asked during the interview.* Participants will not be identified in any reports or publications associated with or stemming from this thesis.

Recording of Data:

As the interviews with participants will be a continuous dialogue between the researcher and the participant, audio recording will be used to ensure accurate transcription of information post-interview. Checkboxes are provided below to indicate agreement, or not, to the use of an audio recording device during the interview.

Storage of Data:

Data, such as any transcript of the interview, will be stored in the locked office of the supervising professor Dr. Adrienne Peters, along a USB drive with recorded audio conversation. The audio files will be encrypted and password protected. Only the researcher will have access to the data, or the supervising professor. All forms of primary data will be kept for a minimum of five years, as required by Memorial University policy on Integrity of Scholarly Research. After five years, paper data such as transcripts may be destroyed, while audio files may be retained indefinitely.

Reporting of Results:

Reporting of data collected will be used in a graduate thesis and subsequent academic publications, following submission to the supervising professor and successful completion of thesis defence. It may also be referenced in conference presentations, or academic publications. The thesis will be available for the public through the QEII library and will be available for access online at <http://collections.mun.ca/cdm/search/collection/theses>.

Sharing of Results with Participants:

Participants may obtain a copy of the paper following its submission on June 30, 2018, at which point a copy will be provided to them by email. Participants will be informed if the paper is used or referenced in other contexts such as publications, conferences, trainings etc.

Questions:

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study, please contact: Katharine Dunbar Winsor – kwinsor@mun.ca 819-434-1977 or Dr. Adrienne Peters apeters@mun.ca 709-864-2665

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

You have read the information about the research.

You have been able to ask questions about this study.

You are satisfied with the answers to all your questions.

You understand what the study is about and what you will be doing.

You understand that you are free to withdraw from the study without having to give a reason and that doing so will not affect you now or in the future.

You understand that any data collected from you up to the point of your withdrawal before June 30, 2018 will be destroyed.

If you sign this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your signature:

I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

I agree to be audio-recorded during the interview.

Yes No

I agree to the use of quotations attributed to a pseudonym.

Yes No

A copy of this Informed Consent Form has been given to me for my records.

Signature of participant

Date

Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

 Signature of Principal Investigator

 Date

Your signature:

I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

I agree to be audio-recorded during the interview.

Yes No

I agree to the use of quotations.

Yes No

A copy of this Informed Consent Form has been given to me for my records.

 Signature of participant

 Date
Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of Principal Investigator

Date

APPENDIX D

Letter of Recruitment

The impact of social supports on experiences of justice involved individuals with fetal alcohol spectrum disorder in Newfoundland and Labrador.

I am inviting you to participate in a brief interview that will take approximately 45-60 minutes and will be conducted by phone. As part of the graduate program in Sociology at Memorial University, I am conducting interviews under the supervision of Drs. Adrienne Peters and Rosemary Ricciardelli on the impact of social supports on experiences of criminally involved individuals with fetal alcohol spectrum disorder (FASD) in the Newfoundland and Labrador.

You can choose to withdraw from the study at any time during the interview and afterwards up to June 30, 2018. Attached you will find a copy of a letter of information about the study in full detail. Participation in this research is voluntary, thus there is no obligation to participate. If you choose to participate, your involvement will not be shared with superiors or other individuals.

I would like to thank you in advance for your time and consideration. If you are interested in participating in this research, or have any questions about this research, please contact Katharine Dunbar Winsor or supervisors Drs. Adrienne Peters or Rosemary Ricciardelli at the information listed below.

Katharine Dunbar Winsor BA
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Department of Sociology
Memorial University of Newfoundland and Labrador
819-434-1977
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Dr. Adrienne Peters
Assistant Professor, Sociology
Memorial University of Newfoundland and Labrador
709-864-2665
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Dr. Rosemary Ricciardelli
Professor, Sociology
Memorial University of Newfoundland and Labrador
709-864-7447
ricciardell@mun.ca

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.