

EMERGENT RESEARCH IN THE FIELD OF FASD FOR COUNSELLING

Implications of Emergent Research in the Field of Fetal Alcohol Spectrum Disorder (FASD) for
Counselling Practice

By

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Dedication

This thesis is born from a place of social justice, compassion, and desire for understanding. I am inspired and humbled by the mothers I have worked with who continue to advocate for their children and resist social responses that limit their voices. I am encouraged by individual practitioners who are beginning to listen to those voices and dedicate their own practice to working with rather than doing to; inspiring many more, like me, who are willing to pick up the forward momentum. Challenging the status quo can be rewarding work; albeit lonely at times. This educational journey is also dedicated to my beautiful children who have patiently waited for their mother to turn her computer off.

Abstract

The purpose of this study is to explore the connections between emergent biomedical research in the field of fetal alcohol spectrum disorder (FASD) and mental health, and how clinical counselling is influenced by it. Two particular areas of research have been demonstrated to affect behaviour in the FASD population: iron deficiency that contributes to chronic sleep deprivation and the impact of the microbiome on mental health. A literature search for counselling approaches was conducted as well as categorization of research sessions at the annual FASD research conferences in Vancouver, BC to understand research directions in the world of FASD and available literature that supports clinical counselling approaches. The implications for counselling practice are examined as well as recommendations for theoretical approaches in clinical counselling. The results demonstrate a lack of literature on counselling intervention practices, evaluation, and theoretical approaches specific to the FASD population. Much of this research reflects a need for further research into clinical intervention and evaluation.

Keywords: FASD, fetal alcohol, counselling, microbiome, sleep

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Chapter 1: Introduction

Fetal alcohol spectrum disorder (FASD) is a complex disorder. FASD is a condition that is caused by the consumption of alcohol during pregnancy; the complexity is in why women drink during pregnancy and how the disorder presents in an individual. Initially, FASD was considered to affect growth and cause cranio-facial abnormalities and intellectual and learning disabilities (Cook et al., 2016). However, Cook et al. (2016) assert that FASD has a much broader spectrum of presentations and disabilities including physical and mental health issues. Across the lifespan, FASD becomes more complex with contributing environmental and social aspects such as parental mental health, substance use, Ministry of Child and Family Development (MCFD) intervention, trauma, misdiagnosis, and sleep and nutritional issues (Chudley, 2018; Gato et al., 2018; Kambeitz et al., 2019). While more and more research is being done to understand prevention, biological markers, justice, diagnostics, behaviour, and medication through research networks in Canada such as the Canadian FASD Research Network (CanFASD) and the University of British Columbia's Interprofessional Conferences on FASD, there is still no clear understanding of how intervention or the counselling piece fits in (Choate & Badry, 2019). We know that more than 90% of individuals with a diagnosed FASD have comorbid mental health issues (American Psychiatric Association, 2013) and are 9 times more likely to be in foster care (Kambeitz et al., 2019); but therapists who specialize in FASD are but a handful in British Columbia. The cause of FASD is simple, the reasons for why it can never be preventable are complicated. This is not a chicken-and-egg scenario where we wonder which came first, FASD or at-risk mothers. Protecting the child starts with protecting the mother.

In the last few years, there is a sense of shifting focus in research from an emphasis on the brain-based etiology of FASD to the physical manifestations of exposure; such as, the role of

the microbiome and sleep in affecting the immune system and behaviour. This is important in gaining more information about this population; however, the research still remains at arms-length from the individuals we work with. The counselling profession, for example, is left to connect the dots in terms of approach and method of engagement with the FASD population. Evaluation of counselling approaches specific to those affected by FASD and assessment tools for individual needs are not yet readily available to the counselling profession. Myles Himmelreich (n.d.), a motivational speaker who also lives with FASD, has a powerful message in one of his videos on his website: “I am not broken, I do not need fixing.” Himmelreich contends that the many systems of engagement and treatment (e.g. school, justice, and medical) even (mis)diagnoses to a certain extent, are reliant on behaviour and often informed by stigma. As a therapist, do we see the behaviour, the learning disability, or someone doing the best they can? Are we really seeing what we think we are seeing?

This paper aims to:

- Examine the underlying social and environmental reasons why women drink during pregnancy;
- Discuss emergent biomedical research that is informing some of the behavioural responses we see;
- Highlight the lack of available research and evaluative literature on counselling approaches; and,
- Discuss considerations for creating accessible clinical approaches with better evaluation and assessment of counselling techniques.

Purpose of Study

Front line service providers, including counsellors, predominantly see behaviour management of children through a neurological lens. That is, the diagnosis of anti-social behaviours such as attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD), anxiety, and depression are predicated on the assumption of a neurological disorder. Case conceptualization, therefore, is predominantly centred around interventions that are based on behaviour modification therapies and medications that strive to manage challenging or harmful behaviours as a result of a disease of the brain. What advocates for people who are affected by FASD, like Himmelreich (n.d.), contend, is that FASD can create, as Szasz (1960) describes, *problems with living*, as opposed to issues stemming from a diseased brain. Szasz posits that what we term mental illness is more to do with expressions of one's struggle with "the problem of *how* [one] should live" as opposed to neurological disease (p. 117).

Research into the microbiome and chronic sleep deprivation, from the context of FASD, highlights the impacts of biological "disease" on the brain while enabling a separation from Himmelreich's (n.d.) concept of *not being broken* and *not needing fixing*. When we can see FASD from the perspective of problems with living, as well as biological barriers, case conceptualization is opened up to include not just a disease focus, but *strategies for living*. How can the plethora of emergent research about the effects of alcohol on the brain and body support the development of counselling techniques that provide a spectrum of care rather than a narrow window?

Personal Connection

I worked as an FASD Key Worker for five years in a rural community. I served families with children with diagnosed or suspected FASD, as well as children with a diagnosed or

suspected complex developmental behavioural condition. I saw children from birth to 18-years-old living in biological, adoptive, or foster families. The position I held is typical of many FASD Key Worker positions where chronic underfunding contributes to long wait lists, reduced service hours, and limited training. In a response to the 2018 Federal Budget announcement, Audrey McFarlane (2018), Executive Director of the CanFASD Research Network in Canada, expressed “surprise” that “not a cent” of the \$300+ billion earmarked for services in Canada had been “allocated to research, education, or interventions for the 1.3 million Canadians, approximately 4% of our population, who have Fetal Alcohol Spectrum Disorder (FASD).” McFarlane pointed out that FASD affects three times more Canadians than Autism Spectrum Disorder with “remarkably little public discussion and urgency on the topic.”

The grave reality is that effects of alcohol exposure are not limited to the functioning of an individual. My work introduced me to the lived experiences of families: poverty, trauma, violence, frustration, mental health barriers, substance use, and isolation. I was also invited to see resilience, strength, and dignity. These families inspire me to learn more and “do better.” My only access to training, such-as-it-was, were the FASD conferences hosted by the University of British Columbia in Vancouver, BC. I was able to connect with diagnostic clinicians from Sunny Hill Children’s Hospital, international researchers, and other provincial Key Workers. While these conferences offered sessions on research with zebra fish, FASD biomarkers, justice issues, medication use, community-based research, diagnostics, and many others, it was through conversations with fellow Key Workers and adults with FASD that I began to understand the wide-ranging nature not only of FASD, but of the system of services set up to support individuals and families. Essentially, Key Workers across the province of BC do somewhat different jobs under the same job description with differing levels of support; the role of Key

Worker is meant to be flexible and responsive to community needs and existing services.

Ogourtsova et al. (2018) contend that families with children with developmental disabilities can experience higher levels of stress, increased mental and physical health challenges, and adverse changes to family dynamics; further, our health-care service models are not standardized nor flexible enough to contend with a rising number of families in need. Wait lists for services are often long and service gaps and duplication can be frustrating for families. In many of the families I worked with where the biological mother still had custody of her child(ren), there was a lone, female-led family, living with poverty, nutritional concerns, marginalization, stigma, behavioural issues, chronic sleep deprivation, multiple mental health diagnoses, abuse, substance use, past or present ministry intervention, and medication for most if not all family members. Morton Ninomiya (2015) points out the contradiction of stigmatization: a diagnosis of FASD can be stigmatizing as can be the secondary disabilities of adverse behaviours that are misdiagnosed and misunderstood from not receiving an accurate diagnosis. When we conceptualize a course of treatment for a child without fully appreciating the scope of etiology and challenges, Morton Ninomiya (2015) argues that we can fall into the trap of “legitimiz[ing] deviant behaviours as illnesses through the work of medical diagnoses” (p. 40).

It was common in my experience as Key Worker that families would seek support when the child, usually a boy, was six to eight years-of-age. The families would site behavioural issues as the main concern. These behaviours included consistently not listening, not following rules, hyper-activity, taking toys or objects from others, leaving the classroom, and confabulation, or creating false memories. Often these children demanded full attention at home and at school. These children were often not included in extra-curricular activities unless there was a full-time adult dedicated to supervising that child. Particularly in families where the child was fostered,

adopted, or being cared for by family members other than the biological parents, it was common to hear stories of neglect, abuse, and trauma. Studies indicate that children with FASD are “three times more likely to be abused or neglected during early childhood than typically developing children” (Zarnegar et al., 2016, p. 552) likely due to a combination of unpredictable, dysregulated emotional responses and limited positive parental skills when a mother is using substances. This was true of my caseload as well as experiences of other provincial Key Workers. The intricacy of FASD is in the lived experience of a child and their family, playing a vital role in determining how FASD shows up for the individual.

There are a wide array of community agencies, organizations, and outreach programs potentially involved with families including the Ministry of Child and Family Development (MCFD), the Ministry of Social Development and Poverty Reduction, Child and Youth Mental Health (CYMH), Adult Mental Health and Substance Use (MHSU), Special Education and Individual Education Plans (IEP) through the school district, specialist and family doctors, behavioural interventionists, and supportive outreach programming through non-profit organizations. While these services and resources can be helpful for the family, navigating them is often overwhelming, especially in rural communities where some of these services require travel to neighboring centres.

The majority of available information on FASD and treatment approaches is focused on children and youth (Moore & Riley, 2015). Much of the information shared here, therefore, is based on this demographic; however, many of the parents or guardians are affected by FASD and trauma, too, whether directly affected themselves or indirectly through responses to the lived experience. These parents are doing the best they can. Interventions for these children include reward and punishment systems, medication, behavioural modification, confinement, and, in

many cases, removal of the child. The system of care for these children and families does not look beyond behaviour. We do not punish a child in a wheel chair for not climbing the stairs; we need to look beyond the behaviour in children with an invisible disability.

Process

This study examines the current biomedical research that is being linked to mental health; specifically, how the microbiome and chronic sleep deprivation influence mental health from a biological perspective. Links between biology and mental health, acute versus chronic models, and the determination of how FASD shows up in a person affect how clinical counsellors determine case conceptualizations and provide treatment. Chapter Two discusses many of the contributing aspects regarding why FASD itself is a misunderstood disorder as well as an analysis of why women drink. I discuss the impacts and influences of co-morbid diagnoses, stigma, and limited professional knowledge to the lived experience. Chapter Two also discusses how assessment and diagnosis can contribute to misunderstanding, misdiagnosis, and misdirection. It introduces emergent research into the current etiology of what is known about the FASD diagnosis and social factors that contribute to its prevalence.

In Chapter Three, I discuss the methodological approach using three hypotheses: research on counselling approaches, theories, or strategies for children living with FASD are difficult to find; research on intervention is predominantly cognitively-based and focused on siloed areas such as trauma, ADHD, or anxiety; and, research on how the microbiome and sleep affect children living with FASD is still emerging and therefore connections to FASD counselling approaches are limited. I conducted a literature search for therapeutic counselling approaches as well as a detailed examination of emerging research categories within the FASD field. In this way, I was able to cross-reference how emerging research is affecting practice. I categorized the

type and number of conference sessions at the annual International FASD conferences held in Vancouver, BC from 2005-2019 to determine the progression of areas of interest in FASD research. In Chapter Four the findings of this analysis are outlined. Finally, Chapter Five discusses the implications of these findings and outlines key practice recommendations.

Assumptions and Limitations of this Study

This study is first and foremost limited to the complex nature of the subject matter. The complexities of the diagnosis span the complexities of social behaviour and discourse. Canadian content and context have been privileged as FASD can present very differently in different countries in terms of attitudes, prevention, assessment, and intervention. This predominantly limits the findings to the Canadian context. In categorizing the sessions at the FASD conferences I was reliant, to some degree, on the short descriptor of the session in the brochure; this prompted a search of the presenter to determine what, exactly their area of research and/or expertise is in order to categorize it effectively. This may have resulted in some sessions being incorrectly categorized. My biases are framed by my experience of working with predominantly Euro-centric families impacted by FASD in an isolated, rural community on the traditional territory of the tla'Amin people. I am also aware that I identify as cis-gendered, able-bodied, middle-class, and of Euro-settler descent. Finally, I am sister to two Indigenous men who carry the diagnosis of FASD. This is a personal journey for me. My research is undoubtedly influenced by my values and beliefs in social justice.

Chapter 2: Literature Review

The Multifaceted World of FASD

The term Fetal Alcohol Syndrome (FAS) was originally coined by Kenneth Jones and David Smith in their seminal article in 1973. Alcohol exposure during pregnancy affects the developing brain of the fetus. Exposure can cause, to varying degrees, permanent deficits to language, intellectual abilities, memory and learning, attention, executive functioning, motor skills, and visuospatial abilities (Sanders, 2013; Williams et al., 2011) with no two individuals having the same effect. Researchers are also starting to get a clearer picture on the physical aspects of FASD including not just facial dysmorphia but issues with organ development and auto-immune diseases (Himmelreich et al., 2017). Alcohol is considered a teratogen, an agent that causes birth defects. Exposure in utero has a teratogenic effect on the central nervous system (American Psychiatric Association, 2013) and contributes to a host of long-term chronic diseases (Moritz, 2017) and secondary disabilities such as mental health, behavioural, cognitive, social and emotional developmental issues.

The current support systems available to children and youth with FASD primarily focus on the problem areas; in particular, behavioural issues and anti-social challenges such as impulse control, self-regulation, and inappropriate sexualized behaviours. Support systems include school, counselling, community non-profit outreach, medical, and mental health. Dubrovsky (2015a) empathically points out that children with FASD can be extraordinarily frustrating to deal with both from the perspective of professionals and family. Conceptualizations for modifications to behaviour are not always communicated well to the child and family and the reasons for treatment are not always clear (Himmelreich, n.d.). Implementation of behavioural modifications are not often sustainable by the parents for any length of time mainly because the

lens of the professional is siloed, or specific to one area of focus; for example, a school-based lens that would not necessarily include barriers to attaining quality sleep. In this case, the focus might be on behaviours needed to address academic levels with no understanding or professional knowledge/jurisdiction of the impact chronic sleep deprivation might be having on daytime function and why. Professionals base their interactions and treatment on medical models, organizational funding, and accreditation requirements that do not always take into consideration the holistic lived experience of the child and their family regardless of a biological or adoptive situation (Hubberstey et al., 2015). Hubberstey et al. (2015) further point out that data collection, accountability and reporting is based on the organization's maintenance of program contracts and measuring hours used rather than on what the client may actually need. For example, the FASD Key Worker program, perhaps the program most holistically involved with families living with FASD, has not incorporated current research into its program standards; the last published document on these standards was released in 2009 (Ministry of Children and Family Development, 2009).

Hubberstey et al. (2015) contend that without an evaluation framework to determine the efficacy of programs serving the FASD population, we cannot be sure which, or how, social health determinates are contributing to the outcomes we are seeing, whether positively or negatively. This includes why women drink during pregnancy, how diagnostic terminology can be perplexing, and the extent to which co-morbid, or misdiagnosis, impacts how we see the child. Understanding the diagnosis itself is only one small aspect of how we engage from a therapeutic perspective.

Assessment and Diagnosis

Through the years several terms have identified the spectrum of FASD: prenatal alcohol effects (PAE) identifies facial dysmorphic features, developmental delay, and growth impairments; fetal alcohol effects (FAE) identifies cognitive impairment without the physical aspects; partial FAS (pFAS) identifies the person with some of the physical impairment but not all; and, alcohol related neurodevelopmental disorder (ARND) identifies those with few or no facial dysmorphic features but demonstrating cognitive and developmental delays. Action papers submitted to the American Psychiatric Association recommend that the term FASD serve as a categorical heading rather than a diagnostic term (Sanders, 2013). Cook et al. (2016) have recently recommended that FASD be used as a diagnostic term that is grouped into two categories essentially removing the “umbrella” descriptor: FASD with sentinel facial features (SFF) (or FAS); and, FASD without SFF (or pFAS and ARND).

Varied terminology can contribute to confusion about what a diagnosis means to the individual, particularly given different diagnostic terminologies between countries; however, the requirement of maternal confirmation of alcohol consumption during pregnancy remains a stigma and barrier to accessing services, a contentious issue for many health care professionals (Morton Ninomiya, 2015). FASD is considered vastly underreported due to the stigma of alcohol consumption for pregnant women. This translates to children being misdiagnosed and lacking supportive services, potentially setting the child up on a trajectory of academic, social, criminal, and mental health struggles. Flannigan et al. (2018a) contend that children with FASD are at a higher risk of experiencing physical and sexualized abuse, neglect, malnutrition, substance use, education disruptions, inappropriate behaviours, trouble with the law, and mental health disorders.

FASD is considered to be the leading cause of developmental disabilities in Canada and worldwide (Millar et al., 2017). While some studies indicate prevalence at about 2-5% (Flannigan et al., 2018b), some studies have estimated FASD prevalence to be as high as 10% for certain groups; for example, children in care, those in the justice system, and some Indigenous communities (Flannigan et al., 2018b). Lange, Rehm, and Popova (2017) indicate even this number is conservative. Resources for and training in assessment is limited. Jonsson (2019) points out the challenge of a disorder that does not have an International Classification of Diseases (ICD) code for administrative and billing purposes: it does not show up in statistical databases.

While the array of adverse outcomes is the same worldwide, diagnostic terms and criteria are not. Anderson et al. (2017) point out a recent study of adoptive and foster youths where a diagnosis of FASD was missed in 80.1% of the youths; further, there was a misdiagnosis rate of 6.4% where ADHD, ODD, learning disabilities, or a communication disorder was diagnosed instead. There has been much debate in academic circles for decades regarding the inclusion of a diagnosis for FASD, in one form or another, in the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2013), considered the gateway to treatment and support services. In the latest edition, the DSM-5, Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure is included in the Conditions for Further Study section (American Psychiatric Association, 2013, p. 798). Critics to a universal, FASD-specific assessment and support program label contend that “current developmental practice emphasizes interaction of function and environment, not etiologic labels” (Klein, 2016, p. 1035). Klein (2016) argues that FASD is “clinically indistinguishable from other causes of neurobehavioural disorders (e.g. antenatal alcohol or other teratogens, complex trauma, genetic)” (p. 1035);

therefore, the treatment regime should be similar. When the etiologic label is emphasized without individualized treatment, it is “misleading to the public and unethical” (Klein, 2016, p. 1035).

Diagnosis of FASD requires a team of professionals who conduct medical evaluations as well as neurodevelopmental assessments. The inclusion of professionals in the multidisciplinary team is based on the degree of suspected exposure to alcohol in utero, age of the child at assessment, timing of the exposure, and genetic and environmental factors; for example, psychologists, developmental pediatricians, neurologists, speech and language clinicians, occupational therapists, and other professional disciplines are included in each assessment as needed (Chudley, 2018). The advantage of this comprehensive assessment is the complexity of the assessment and the recommendations for treatment; while it is the diagnosis that is usually being sought to obtain additional disability services, the recommendations for treatment are far more valuable in terms of ascertaining and supporting the developmental trajectory. A diagnosis of FASD itself is not useful without understanding the symptoms present in an individual.

In terms of assessment, much of the research is now centered on early identification, including biomarker identification (Cobben et al., 2018), analyzing facial shape for neurocognitive correlates (Suttie et al., 2018), and placental markers (Lecuyer et al., 2017). Many professionals argue that an early diagnosis of FASD is key in addressing possible long-term impairments; however, Klein (2016) posits that “equitable, nonetiologic diagnosis-based services for all people with neurobehavioural disorders” (p. 1036) enables a focus on functional impairment rather than attributing potentially stigmatizing causality.

Studies show that FASD becomes more complex across the life-span (Kambeitz et al., 2019). Multiple, complex factors affect the developmental trajectory of any child: parental

mental health, financial stability, nutrition, access to school supports, exercise, sleep, outside versus computer time, and social connections. Sanders (2013) points out that disability services and funding are predicated on a requirement of an IQ below 70. While some children with FASD meet this requirement, about 13% (Sanders, 2013), the vast majority of individuals living with FASD have impairment in executive and adaptive functioning, not intelligence. Intelligence for individuals with FASD is on a spectrum from significant impairment to superior intelligence (Williams et al., 2011); verbal expressive language can be at a much higher level than receptive, giving the impression of comprehension and purpose in actions. This can look like a child (or adult) knows the rules but breaks them intentionally or can look like confabulation, often described by caregivers as “lying” (Brown et al., 2018; Dubrovsky, 2015a).

Further disadvantages to assessment include the high cost of a multi-team assessment and the time it takes to perform them. While the assessment is free to Canadian children up to the age of 18, Chudley (2018) estimates the cost of assessment to be between \$3110 and \$4570 per person (not including subsidies for travel, food, and accommodation for marginalized families living outside the catchment area); further, the total cost of diagnostic services in Canada can run anywhere from a lower estimate of \$3.6 to the higher estimate of \$7.3 million annually. Popova et al. (2016) reference a Canadian survey of all FASD multidisciplinary diagnostic clinics that revealed a 17-fold increase in diagnostic capacity would be needed across Canada to diagnose the number of FASD cases currently in the system. The 17-fold increase was based on a population prevalence of 1%: A figure that vastly underrepresents the (still underreported) 2-5% prevalence indicated by most studies. How do we put a financial figure on something we cannot even measure accurately?

Little research is going into assessment education and tools for front-line health care providers to address the many co-factors to alcohol consumption and antenatal care. Certain populations have been identified as at risk for having a child with FASD (American Psychiatric Association, 2013); however, Kingsland et al. (2018) point out that no controlled trials have been conducted to assess the efficacy and cost benefits of implementing universal assessments and strategies to increase recommended antenatal care specifically addressing the multi-faceted contributors to alcohol consumption during pregnancy.

Why Women Drink During Pregnancy

Singal et al. (2017) point out that women who drink during pregnancy are not intentionally trying to harm their child. At its core, the answer to what causes FASD is consumption of alcohol during pregnancy; in particular, binge drinking in the first trimester seems to have the greatest impact on the fetus as the brain is being formed during this time period. However, no safe limits of alcohol, at any point of the pregnancy, have been determined. The risks of low to moderate consumption are not clear. Further complicating this, is lack of data on the definition of “low to moderate alcohol” (Zizzo & Racine, 2017) with health care providers struggling to provide a consistent message of what “in moderation” means (Coons et al., 2017). The Provincial Outreach Program for FASD in British Columbia exposes conflicting opinions in the medical profession and online about safe amounts of alcohol (POPFASD, 2019). Different cultures, different generations, different circumstances, and different beliefs all contribute to the greater social (mis)understanding of what alcohol is to Canadian culture.

While many health professionals advocate for abstinence if a woman is having unprotected sex or is already pregnant, many online sources of information question the harm of “light” drinking (Khazan & Beck, 2016). Advice women hear from health professionals,

including doctors and midwives, indicate that “light” drinking in the second and third trimesters is not a problem (Crawford-Williams et al., 2015). This was the advice given to me by my midwife. This advice is still being given to mothers by midwives in my community (S. Nordman, personal communication, February 8, 2020). This is not a judgement on the professionalism of midwives or other healthcare professionals; rather, it speaks to how little we actually know about alcohol and pregnancy both biologically and socially. Because the extent of the effects on the fetus from alcohol is dependent on the physical and mental health of the mother, at what stage of the pregnancy the alcohol was consumed, how much alcohol was consumed in each episode of drinking, and the mother’s stress level throughout the pregnancy, no one can say for certain that “light” drinking is, or is not, detrimental to the fetus.

Kingsland et al. (2018) found that in Canada, only 50% of health professionals provide advice to pregnant women on alcohol consumption during pregnancy. Curriculum in Canadian schools and psychiatric programs “are devoid of or contain inadequate content on FASD” (Anderson et al., 2017, p. 71). This fuels many other barriers to providing information about alcohol to women such as lack of assessment tools, fear of stigma, limited clinical time, need for staff training, culturally appropriate resources, lack of referral options, and a lack of understanding of the importance of education around alcohol consumption during pregnancy (Kingsland et al., 2018). In an Ontario study, some professionals surveyed indicated that drinking in the first trimester should be avoided but occasional drinking (e.g. special occasions) in the second and third trimesters “will not harm mom or baby” (Coons et al., 2017, p. 83). This study also highlighted stereotypical beliefs by professionals regarding alcohol use issues. If the woman has no history of alcohol abuse, then advising moderate drinking is acceptable; the underlying assumption being that FASD only occurs when alcohol use problems are identified.

The ease of using the internet and social media sites for finding pregnancy health-related information, advice, and opinions brings to question what a reliable source for consumers of pregnancy information is and how social discourse affects choices (Prescott & Mackie, 2017). Public awareness-raising campaign documents “encourage (and intimidate) women to abstain by employing images, offering advice, and by connecting women and others to prevention services’ phone numbers and websites” (Norton, 2018, p. 134). Norton (2018) contends that these campaigns fail to emphasize the many contributing factors to FASD causation such as poverty, psychological distress, and nutrition; further, neoliberalism has influenced health policy and reform by introducing the concept of the “‘woman’s choice’ discourse” (p. 134). Ironically, this has also led to online opinion pieces such as Graham’s (2016), writing for Slate magazine, who presents the view that because there is no concrete evidence that “light” drinking negatively affects the fetus, why must a woman “swath” herself in “bubble-wrap thinking” that turns pregnancy “into a nine-month slog of joyless paranoia.” Influences on social discourse, such as Graham’s in their critical examination of paternalistic views of pregnancy, illuminate how the roles and behaviours of mothers, and with it the concept of mothering itself, have been “idealized, scrutinized, and denigrated” (Reid et al., 2008). Reid et al. (2008) contend that the “notion of surveillance underpins all of the discourses” (p. 230); that is, social and systemic expectations of a mother’s behaviour together with comments and decisions about her and her child’s fate is omnipresent.

Another aspect of why women drink while pregnant, is that approximately 50% of women have unplanned pregnancies (British Columbia Centre of Excellence for Women’s Health, n.d.), sometimes not recognizing the pregnancy for several months. Further, not all who drink will access assessment for concerns with suspected developmental delays and, of those, not

all will confirm alcohol exposure. Research is telling us that the populations most at risk for consuming alcohol when pregnant are professional women and post-secondary students despite the majority of research focused on minoritized, isolated populations (Norton, 2018; Singal et al., 2017).

The British Columbia Centre of Excellence for Women's Health (n.d.) has identified that women are unaware of or underestimate the harm that alcohol can do to a fetus; further, some effects of alcohol may not be apparent until the child is older. Experiences of seeing women who drink during pregnancy with children who appear to be healthy further confuses medical advice of abstinence. Khazan and Beck (2016), writing an online opinion piece for *The Atlantic*, cite studies that concluded women who were "light" drinkers had *fewer* issues with behavioural problems in their children and higher IQ levels. Not only do the authors fail to report if those children had actually been assessed for FASD, the entire article assumes a privileged view of pregnancy and motherhood. This dominant model of motherhood, the "good mother," is a narrow, pervasive model that excludes diversity while also socially constructing the concept of a "bad mother" (Couvrette, et al., 2016). Norton (2018) names the dangers of prescribing to a heterosexual, cis-gendered, feminine, privileged woman through social discourse on alcohol and pregnancy: it contributes to stigmas and stereotypes for the women who do not fit into this limiting definition.

Why "At-Risk" Women Drink During Pregnancy

One could argue that we have socially constructed (e.g. through awareness programs such as the British Columbia Centre of Excellence for Women's Health, n.d.) all women to be "at risk," with self-control manufactured as the main obstacle to FASD prevention (Norton, 2018). While FASD has historically been described as 100% preventable, we are finally seeing a shift in

the language through national organizations such as the Canadian FASD Research Network (CanFASD), provincial non-profits such as South East Alberta Fetal Alcohol Network (SEAFAN), and multiple provincial government websites. The danger of the “100% preventable” messaging, is it creates stigma and discourages women from seeking supportive, non-judgmental services. How awareness-raising campaigns represent the concerns of alcohol exposure (e.g. fear-based versus support-based) can construct portrayals of women as responsible versus irresponsible and view a child born with FASD as a “potential loss” associated with alcohol consumption (CanFASD, 2011). The perpetuation of images of “damaged” children being used to motivate women to alter their behaviours further stigmatizes women and those living with FASD.

The use of alcohol and/or substances together with poor health practices, poor nutrition, and risky life choices during pregnancy cannot be separated from histories of poverty, violence, sexualized or emotional abuse, and/or living with partners with substance use issues (Singal et al., 2017). This affects all women from diverse backgrounds and socioeconomic status. Rutman (2016) describes a study of 80 birth mothers of children assessed with FASD: 50% of the women had FASD themselves; 95% had experienced physical, emotional, or sexualized abuse; 80% had a major, unaddressed mental illness; more than 75% had post-traumatic stress disorder; and, the majority of these women lived with poverty. Godard et al. (2013) contend that when we focus on what has happened to a woman rather than what is wrong with her, we eliminate language that objectifies her and makes her responsible for the abuse. For example, “co-dependence,” “poor boundaries,” “addict,” and “patient” reduces the woman’s experience to a “problem to be dealt with”. “Intimate partner violence” and “sexual abuse” assumes an intimacy and consent that juxtaposes the violence (Coates & Wade, 2007).

Singal et al. (2017) identify that almost two-thirds of women with a psychiatric diagnosis such as anxiety, depression, eating disorder, or posttraumatic stress disorder use alcohol and other harmful substances. Hubberstey et al. (2019) contend that systemic barriers, such as stereotyping, judgement, and fear of child welfare involvement, prevent women from accessing services, further compounding mental health and substance use issues. Women seeking help are often met with negative attitudes and adversarial approaches by health care providers and child welfare authorities. However, Rutman and Hubberstey (2019) cite research literature that indicates pregnant women respond well to health support with substance use issues when programming is women-centred, non-judgmental, trauma-informed, accessible, relationship-based, and offered with prenatal care. Positive outcomes are further enhanced by addressing and removing social environmental barriers to participation such as transportation, food, child care, and fear of child removal. For the mother, there is a direct connection between social determinants of health, mental health status, environmental risks, poverty, and consumption of alcohol.

While alcohol can be damaging to the growing fetus, the complex determinants of the mother's mental and physical health impact the availability of choices open to her. Rutman and Hubberstey's (2019) research with women at high risk for having a child with FASD highlight that for nearly all the cases examined, substance use, violence, and mental health issues were fully intertwined. Kambeitz et al. (2019) point out that early diagnosis of FASD in a young child has the added benefit of being able to identify a mother for whom alcohol use during pregnancy is emblematic of other determinates of health and an unsafe living situation. More than 70% of women who have had one child with FASD will have another affected child if prevention measures and supports are not offered and/or put in place (Kambeitz et al., 2019).

Current prevention measures are predominantly based on public education rather than on increased, consistent, reliable, accessible, and useful services to new mothers. Many programs use harm-reduction approaches, outreach, and “one-stop” services that are not co-created with other agencies nor are they evaluated (Hubberstey et al., 2015). Rutman and Hubberstey (2019) contend that prevention responses for vulnerable and high-risk women need to align with what we know and understand about the range of issues and challenges rather than a single focus on alcohol and the fetus. Many of these mothers experienced abuse, violence, material disadvantage, and poverty as children and as adults. Health disparities for marginalized populations need to be identified and addressed through alignment of appropriate supports and services (Anderson et al., 2017).

Stigma

It is rare that a disability is named for its cause rather than the founding scientists. Choate and Badry (2019) point out that literature on intervention is far outweighed by the literature on prevalence, incidence and problems. The public perception is focused on negative discourse which informs ethical considerations. Di Pietro, et al. (2016) highlight ethical considerations in research and practice; for example, screening or diagnostic assessments can lead to stigmatization of the individuals and their families, create perceived social and legal risks, and potentially lead to loss of custody. Social discourse frames the risk of FASD as a health issue or moral failure: The rights of the mother and her fetus are juxtaposed. As Di Pietro et al. (2016) point out, there is still only a small body of work examining the impacts of lived experiences of stigma in the FASD population.

Arguments for better prevention and knowledge dissemination regarding the effects of alcohol on the fetus, similar to the tobacco industry and the subsequent advertising on cigarette

packages, have been made. However, an attempt to alter Canada's Bill C-206 to include requirements for clear advertising on alcoholic beverages failed at the committee level (Di Pietro et al., 2016). As a Key Worker I factitiously advocated for the inclusion of condoms with alcoholic beverages; women are not the only ones responsible for the fate of the fetus. While research has investigated biological contributions to FASD through sperm from males exposed to alcohol in animal models (Liyanage-Zachariah & Harding, 2019), perhaps the most telling contribution lies with partners who use alcohol and partners who are violent (Rutman & Hubberstey, 2019). Some research has indicated that over 90% of vulnerable women with children with FASD have experienced physical, emotional, or sexualized abuse (Rutman, 2016). Yet the stigma of women who drink pervades our social discourse, allocation of research funding to female biology in the biomedical field, and the creation of prevention programs for women.

There is a growing social movement within the FASD community with the rallying call "nothing about us without us" (Choate & Badry, 2019, p. 37). Social discourse portrays a negative perspective regarding all things FASD, including biomedical research on the problems of FASD that far outweigh intervention literature, as echoed in my research. This also highlights how biomedical research has been privileged over intervention research. Choate and Badry (2019) recommend further research into social programming, prevention, and clinical interventions.

The pre-conference day session at the 7th International Conference on Fetal Alcohol Spectrum Disorder Research, Results and Relevance on March 1, 2017 in Vancouver, BC, was on stigma in the FASD population. In her introduction, Lutke (2017) declared that ". . . the world of FASD has not, to date, had any significant conversations about stigma and stereotyping" (p. 3). Lutke went on to talk about the profound impacts of shame, poverty, addiction, and mental

health issues that form our social construction of what a FASD person is rather than seeing the human and empathizing with their suffering. In an analysis of the media, a study showed two themes that reflect stigma and FASD: “sympathy for the child and disdain for the biological mother” (Corrigan et al., 2019). In particular, this study revealed attitudes towards the biological mother as being a child abuser, not caring about her child, in denial, secretive, addict, ignorant, living with poverty, having poor social connections, and deserving of harsh treatment. Corrigan et al. (2019) also highlight discriminatory behaviours in the health sector by service providers who lack an understanding of FASD and are unable to identify children with the disorder; this leads to missed opportunities for referrals, misdiagnosis, and compassion for the individual.

Most profound for me, in this research, is Corrigan et al.’s (2019) question regarding the concept of “kernel of truth” thinking. As Corrigan et al. point out, the stereotypes of children with FASD conclude that all children with FASD have impulse issues, attention deficits, and cognitive and social difficulties. Researchers cannot be sure if mental health issues are a primary or secondary effect of alcohol exposure (Kambeitz et al., 2019). If we assume that attention deficits, for example, are a stereotypical symptom of FASD, intervention plans are informed by behavioural modification strategies and medication rather than understanding the implications of environmental barriers such as abuse or poverty and biological contributors like iron in chronic sleep issues or microbiome dysfunction. Further, we also greatly underappreciate the social and behavioural responses to the lived experience of FASD that includes stigma. There is a tension in our systems of care between strong messaging that seeks to minimize in utero harm from alcohol and the judgmental propagation of stigma (Zizzo & Racine, 2017).

Trauma

There is a high prevalence of Canadian children and youth in foster care with FASD (Popova et al., 2014). Children in foster care have a 10 to 40-fold increase in FASD rates compared to the general population (Kambeitz et al., 2019), likely due to life circumstances of the mother (e.g. substance use issues, child abuse, neglect, or young maternal age) which can increase the probability that the child was exposed to alcohol in utero. Hasselle et al. (2019) discuss the many barriers to intervention engagement for women of minoritized populations when there is violence from a partner: they include a higher likelihood of becoming pregnant, an increased risk of violence when pregnant, and fear of lethal retaliation by the partner if the woman seeks help. The cycles of trauma for individuals living with FASD are found in utero, in childhood, as youth, in the school system, in the justice system, and back to utero.

Any therapeutic approaches undertaken with individuals affected by FASD must include a compassionate trauma lens, or, as O'Neil (2017) describes, an adverse childhood experience/adverse lived experience lens. Children living with FASD have a 9 times higher likelihood of being in foster care and are 6.7 times more likely to be placed in residential care (Kambeitz et al., 2019). Children with FASD, who are also exposed to early trauma, are more likely to experience challenges in attention, emotional and behavioural issues, intelligence, memory, and speech and language as opposed to one exposure in absence of the other (Price et al., 2017). Overall, Price et al. (2017) found that children with both exposures, alcohol in utero and trauma in early childhood, experienced more social and behavioural difficulties. Attachment disorders are common in the FASD population (Brown et al., 2018); one study identified a 61% prevalence rate of reactive attachment disorder (Brown & Harr, 2018). Attachment theory has been politicized and used as a clinical and social welfare tool to assess, explain and marginalize

the parent (mother)-child relationship without recognition of how culture, economics, and biology are enmeshed in social responses (Duschinsky et al., 2015). O'Neil (2017) argues that we cannot define trauma without understanding the lived experience. "You cannot consequence out a triggered response" (O'Neil, 2017, 20:28).

The diagnosis of FASD assumes cognitive functioning is affected; individuals are generally treated as though cognitive functioning is the only aspect of their diagnosis. However, the missing link to therapeutic approaches for this population is a keen understanding of the profound impact adverse childhood experiences has in their lives (Kambeitz et al., 2019), both from the perspective of how we treat the child and how we approach the mother. Professional therapeutic approaches all have at their heart an ethical assumption that services are individual-centric, that the parent is the expert. However, Morton Ninomiya's (2015) research revealed a disconnect: Parents are required to be experts not only for their child's needs, but in navigating the institutions and systems they rely on for services and funding. In turn, these systems and institutions do not see or treat parents as the expert. Despite the large amounts of information available to service providers and health care professionals, stigma is reinforced within the systems of care (Zizzo & Racine, 2017) potentially perpetuating trauma.

Co-Morbid Diagnoses

Another aspect of diagnosis and assessment that is not considered, particularly given a reliance on maternal self-report, are children without maternal confirmation, whether through fear of stigma or apprehension, or, in the case of foster and adoptive children, limited access to the mother and/or her family. Diagnosis, then, is reliant on behavioral cues; for example, the child who has been exposed without maternal confirmation may be diagnosed with a myriad of co-morbid diagnoses common to individuals with FASD such as attention-deficit spectrum

disorder (ADHD), oppositional defiant disorder (ODD), depressive disorder, and/or living with an anxiety disorder (American Psychiatric Association, 2013). If the family health care provider has not been trained or has limited access to information regarding FASD, the full picture of the individual may be missed and the focus will be on behaviour modification and medication rather than underlying symptoms contributing to the behavioural issues such as FASD. As a FASD Key Worker, referrals to my program for complex developmental behavioural disorders sometimes would lead to a suspected FASD. For example, it is very common to see a child who presents with diagnoses of ADHD and/or ODD and/or anxiety, is a non-sleeper, picky-eater, and disorganized thinker. Dubrovsky (2015b) demonstrates that for children with FASD, the problem is not simply defiance (ODD) or distraction (ADHD); rather, the issue is in not being able to recall the information when needed, referred to as limited access to working memory.

Behavioural strategies for ADHD and ODD are not effective in individuals with FASD because the working memory is impaired. Consequences, rewards, and punishments are ineffective at behavioural modification because behavioural modification is dependent on executive cognitive function.

In a co-morbidity meta-analysis study of individuals with FASD and the general population in the United States, Popova et al. (2016) determined that individuals with FASD were 8 times more likely to be diagnosed with an attention deficit disorder, 97 times more likely to be diagnosed with an intellectual disability, and 11 times more likely to be diagnosed with a receptive language disorder. Of the individuals in the study, 90.7% had a comorbid diagnosis of conduct disorder including behavioural problems, disruptive behaviour and/or impulsivity. Young et al. (2016) point out that while FASD is defined with a clear etiology, ADHD is diagnosed descriptively. Further, the authors contend that a clinical presentation of ADHD alone

is different from the presentation of ADHD with FASD. If a child has not been diagnosed with FASD, if the mother is not willing to confirm alcohol consumption, and/or the doctor has not asked about alcohol consumption during pregnancy, it is very difficult to always make an accurate diagnosis and treatment plan.

Another consideration for co-morbid diagnoses is the presence of adverse childhood experiences (ACEs). There is a strong correlation between ACEs, neurodevelopmental disorders, and FASD. In their study, Kambeitz et al. (2019) demonstrated that ACEs are much more common in individuals with a diagnosed FASD; further, individuals with FASD are at increased risk of comorbid neurodevelopmental disorders over the lifespan. As the authors point out, this has direct implications for the severity of FASD as well as burden of care. The diagnosis of FASD and the subsequent life trajectory crosses many systems including medical, mental health, addictions, justice, poverty, and education. Social services, foster care systems, child protection services and youth justice experience huge demands on case management for children with a diagnosed or suspected FASD. Anderson et al. (2017) point out that the conversations surrounding the relationship of FASD and psychiatric risk have led to difficulty deciphering whether the presence of FASD itself is the risk factor (co-morbid) or if individuals with FASD are at more risk for developing co-occurring mental health diagnoses.

Emergent Research

Research is beginning to find evidence that FASD is not simply the mental health diagnosis it was once thought to be. Discussion of the microbiome and sleep are important considerations in terms of therapeutic approaches because they impact behaviour. No matter how many rewards and punishments you offer to a child in a wheelchair, he will not be able to walk up the stairs. Similarly, if we do not include the possibility of physical and biological etiology,

such as chronic sleep deprivation and under-functioning microbiome, we cannot simply change the behaviour.

The Microbiome

Psychiatry has been making some concrete connections between mental health and the health of the microbiome in the last five to six years (O'Mahony, 2017). Speaking at the 8th International Conference on Fetal Alcohol Spectrum Disorder in Vancouver, British Columbia, Dr. Tamar Gur (personal communication, March 7, 2019) explained that "psychiatry was sort of late to the game in terms of thinking about the microbes". There are many reasons to see how microbiota can be involved with psychiatric disorders including understanding depression as an inflammatory disorder (Weinberg, 2019). Gur explained that there is "very direct talk between the microbes in your body and the immune system" as well as identifying that pre- and probiotics are able to influence behaviour. Microbiota research is the "new frontier" in unravelling how the mechanisms of prenatal exposures (e.g. alcohol and stress; O'Mahoney, 2017) together with diet (Stevens et al., 2019) affects the microbiome which in turn contributes to psychiatric disorders.

Signs and symptoms that the symbiotic relationship between the host and gut microbiota are in dysbiosis include inflammatory bowel disease (IBD), irritable bowel syndrome (IBS), allergies, autoimmune diseases such as arthritis and asthma, and brain disorders (Tanaka & Nakayama, 2017). This is significant given a preliminary study on 541 adults diagnosed with FASD: The report indicated that autoimmune diseases including celiac disease, ulcerative colitis, Crohn's disease, asthma, and fibromyalgia were 4-6 times higher in the FASD population (Himmelreich, et al., 2017).

Intestinal bacterial colonization profoundly affects the development and physiology of the immune system in early life and health and disease in later life. Tanaka and Nakayama (2017) contend that there is a “critical window” for gut microbiota development in infancy where disturbances to the process can cause immune diseases such as food allergies, skin conditions and asthma. It is believed that the gut microbiota reach maturity by age three years in the host. Gato et al. (2018) note that an under-established microbiome in the first three years can lead to “significant delays or deficits in brain development” (p. 1199) leading to behavioural concerns in early childhood. Nguyen et al. (2016) contend that nutrition is a vital risk factor for children with FASD including abnormal eating behaviours, poor appetite, impaired satiety control, constant snacking, and delayed skills in self-feeding. The authors found that children with FASD consumed fewer nutrient dense foods than their peers indicating a vulnerability to healthy cognitive development.

Adverse early experiences and trauma also affect health across the lifetime (Harris, 2015); this begins in utero. “Clear links were found between maternal prenatal stress and the infant intestinal microbiota and health” (Glover et al., 2018, p. 848). Nguyen et al. (2016) report an increase in the effects of alcohol exposure on the fetus when the mother’s nutritional intake is poor; further, there is evidence that exposure in utero influences early stress and pain reactivity (cortisol stress response) with implications for later health and behaviour impacts (Oberlander et al., 2008); for example, even moderate prenatal exposure can cause significant inflammatory responses leading to chronic pain starting in the early years (Noor & Milligan, 2018).

Approximately 65% of people diagnosed with FASD are pre-mature (Popova et al., 2016); these births can often involve a high degree of medical intervention including incubators, antibiotics, and steroids. Antibiotic use in early life can have devastating effects on the

development of the gut microbiota (Tanaka & Nakayama, 2017). Tanaka and Nakayama (2017) posit antibiotic use increases the likelihood of developing environmental allergic diseases such as asthma, eczema, and type 1 diabetes. Himmelreich et al. (2017) also found that individuals living with FASD were 147 times more likely to have chronic ear infections. Given ear infections are commonly treated with antibiotics, this is staggering.

Sleep

Like many other aspects of how FASD shows up in our minds and bodies, little is known about sleep and FASD. “Sleep is... the golden chain that ties health and our bodies together” (Dekker, as cited by Dr. Ana Hanlon-Dearman, personal communication, March 9, 2019); it is crucial to early brain development. As Dr. Hanlon-Dearman explained in her presentation at the 8th International Conference on FASD in Vancouver, BC, sleep difficulties are common in children living with FASD, about 85%. Research demonstrates that sleep difficulties in childhood lead to long-term chronic sleep impairments in adulthood that exacerbate long-term cognitive and behavioural consequences of FASD (Inkelis, 2019). This is echoed by Ipsiroglu et al. (2012); longitudinal studies reveal that children living with FASD are at high risk for developing chronic sleep problems “triggering daytime behavioural co-morbidities such as inattention, hyperactivity, and cognitive and emotional impairments” (p. 76). Dr. Hanlon-Dearman explained that children do not express a feeling of tiredness like adults do; we see hyperactivity, disorganized thinking, aggression, increased sensory symptoms, and behavioural strategies, like sleep hygiene recommendations, are not working.

Inkelis and Thomas (2018) posit that while sleep disturbances are perhaps the most common comorbidity with prenatal alcohol exposure (PAE), health care providers generally fail to properly assess for them, primarily because it is parents who go to their doctor with

complaints of day time behaviours rather than recognizing sleep is the contributing factor. For this reason, “sleep disorders frequently go undiagnosed and untreated” (Inkelis & Thomas, 2018, para 37). If sleep issues are noted, melatonin seems to be the go-to in terms of therapy. Research indicates that a high percentage of individuals with FASD have abnormal melatonin secretion (Inkelis, 2019). Melatonin supplementation, therefore, is a common sleep therapy recommended by doctors, and common in the families I worked with. However, melatonin is actually classified as a dietary supplement, meaning, it has not been evaluated for safe use in children nor is it regulated in terms of standards in purity in the many different brands and forms offered (Inkelis & Thomas, 2018); further, studies have not been done on how melatonin supplements interact with prescribed stimulant medications.

At the heart, there still remains a reliance on pharmaceuticals to treat the behavioural symptoms of FASD. During a presentation of their longitudinal study results on sleep and FASD at the 7th International Conference on Fetal Alcohol Spectrum Disorder in Vancouver, BC, Dr.s Osman Ipsiroglu and Amy Salmon (Personal communication March 2, 2017) told the audience that if we can figure out the iron deficiency conundrum in children living with FASD, essentially chronic sleep deprivation, we can eliminate the use of medications to control daytime behaviours for the rest of their lives. Ipsiroglu presented evidence that some stimulants, such as Ritalin, further inhibit iron uptake which increases sleep issues which in turn increases day time behaviours; a common mistake by prescribing doctors is to increase the stimulant when it appears to not work at lower doses.

Chapter 3: Methodology

At the centre of this research is the overarching question of how to support individuals living with FASD from a counselling lens. Given the growing amount of research into what FASD potentially looks like, how does a clinical counsellor put all the pieces together? To answer the central research question for this study, namely, what are the implications for counselling practice of emergent research on assessment and intervention with behavioural challenges in children with a suspected or diagnosed FASD, I examined the following hypotheses:

- Research on counselling approaches, theories, or strategies for children living with FASD is difficult to find as much of this information is shared verbally (e.g. through presentations and conferences) rather than academically (e.g. through peer-reviewed studies);
- Research on intervention is predominantly cognitively-based and focused on siloed areas such as trauma, ADHD, or anxiety; and,
- Research on how the microbiome and sleep affect children living with FASD is still emerging and therefore connections to FASD counselling approaches are practically non-existent.

The literature review was specific to Canadian sources on counselling strategies and process but given the limited availability of sources of information, some international literature was included.

Academic Literature Review

Hypothesis 1: Research on counselling approaches, theories, or strategies for children living with FASD is difficult to find.

Key words included: fetal alcohol+counseling; counsel* fetal alcohol; fetal alcohol; (fetal alcohol) AND (counsel* approaches) NOT diagnosis NOT treatment; fetal alcohol+counsel* framework. Criteria for eligibility were:

- Related to children and youth;
- Specific counselling or clinical approach as part of the research; and,
- Recommendations of specific counselling or clinical theory or approach as part of treatment.

The databases under counselling/psychology/human services searched were:

- ProQuest;
- Taylor & Francis Online;
- Sage Premier;
- Psychology and Behavioural Sciences Collection; and,
- Google Scholar.

The search yielded a great deal of sources related to what FASD is, diagnosis, prevention, justice issues, and front-line and outreach programs but very limited results in terms of research, studies, or evaluation of counselling programs or frameworks that directly support this population.

The search was then refined to compare seven different key areas associated with FASD across the same five data bases. The key words used were trauma+child*+counsel*, sleep+child*+counsel*, anxiety+child*+counsel*, ADHD+child*+counsel*, FASD+child*+counsel*, (fetal alcohol)+child*+counsel*, and microbiome+child*+counsel*. In this way, a comparison of available resources, studies, and research could be made. Criteria for eligibility was the same for the more general search identified above.

Open Access to Academic and Professional Research Online

Hypothesis 2: Research on intervention is predominantly cognitively-based and focused on siloed areas such as trauma, ADHD, or anxiety.

As has been discussed in the research, FASD is a diagnosis which can include anxiety, anti-social behaviours, attention deficits, and learning disabilities, as well as many physical and biological issues including microbiome and sleep. I searched professional organizations online whose focus was either mental health and/or FASD related. As the search engines on these websites are limited, key words were used but not parameters on publication dates (2015-2020) or peer reviewed.

- The Canadian FASD Research Network (CanFASD): The focus of CanFASD is on prevention, diagnosis, intervention, child welfare, and justice. The network facilitates national collaboration on research that is shared with all Canadians. I reviewed CanFASD's sections on Research Priorities, Lifespan Intervention, and general queries using counsel*, microbiome, sleep, and mental health.
- Canadian Counselling and Psychotherapy Association (CCPA): The CCPA is a national association of registered counsellors with limited information on mental health topics. I searched for trauma, sleep, anxiety, ADHD, FASD, and microbiome.
- Centre for Addiction and Mental Health (CAMH): CAMH is a Canadian mental illness research facility. I searched for trauma, sleep, anxiety, ADHD, FASD, and microbiome.

Focus of FASD Research: Vancouver Conferences

Hypothesis 3: Research on how the microbiome and sleep affect children living with FASD is still emerging and therefore connections to FASD counselling approaches are limited.

I categorized the topics from every International Research Conference on Adolescents and Adults with FASD (even years) and the International Conference on Fetal Alcohol Spectrum Disorder (odd years) from the beginning, 2005 to 2020 (2020 Conference was cancelled due Covid-19 but the brochure had already been printed). This data demonstrates the focus year-to-year on FASD research; it provides an understanding of where research interest and dollars are being spent. As well, it suggests other areas that would benefit not only from more research, but through a better evaluation process.

Chapter 4: Results

The search for research connections between FASD and counselling and emergent research on microbiome and sleep is challenging. This study indicates that while there is a great deal of information out there on education about what FASD is and what it looks like, only a few articles spoke to theoretical mental health approaches used within this population (Choate & Badry, 2019). No studies on the use of theoretical approaches or evaluations for counselling currently being used that included FASD and microbiome or FASD and sleep were found.

Counselling Approaches, Theories and Strategies

An initial search for academic literature limited to counselling, FASD, microbiome, and sleep yielded only few results. A search for FASD and counselling yielded only a few results as well. Given that over 90% of individuals with a diagnosed FASD also have a comorbid mental health diagnosis (Cullen et al., 2013; Popova et al., 2016; Young et al., 2016), with contributing biological factors relating to challenging behaviours (Ntranos & Casaccia, 2017; Stevens et al., 2019), this was an interesting discovery. It became apparent that in order to understand how diagnosed mental health issues are treated in the FASD population, I needed to compare apples-to-apples across several co-occurring mental health diagnoses; that is, use the same search words for several commonly diagnosed disorders, namely, anxiety, trauma, and ADHD as well as sleep and the microbiome. In this way I was able to compare the amount of research and available articles on each topic. I counted eligible articles in the first 40 responses. Some searches yielded less than 40 responses; this is indicated in Table 1 below.

Table 1*Comparison of Responses Across 5 Different Databases*

Database	Search Words						
	Trauma+ child*+ counsel*	Sleep+ child*+ counsel*	Anxiety+ child*+ counsel*	ADHD+ child*+ counsel*	FASD+ child*+ counsel*	(fetal alcohol) +child*+ counsel*	Micro- biome+ child*+ counsel*
ProQuest	20	20	21	15	0 of 17	0	1 of 19
Social Sciences							
Taylor & Francis	11	14	15	15	0	0	0
Mental Health Psychology and Behavioural Sciences	9	4 of 27	13	7 of 26	0	0 of 2	0
Sage Premier	11	16	11	6	1 of 3	2016- 2020 1 of 13	0 of 3
Google Scholar	14	6	16	14	1	1	0

The results indicate that for FASD, fetal alcohol, and microbiome searches, very little is available. It is also important to note that none of the articles found for trauma, sleep, anxiety, or ADHD included reference to FASD, fetal alcohol, or microbiome. As noted previously, only 50% of health professionals provide advice to pregnant women on alcohol consumption during pregnancy (Kingsland et al., 2018) and Canadian schools and psychiatric programs do not contain adequate content on FASD (Anderson et al., 2017). This does not seem to be such a surprise given the lack of research available.

Cognitive- Versus Biologically-Based Approaches

Table 2 demonstrates that trauma and anxiety have the most available responses on each website with CCPA having a much greater number of responses for sleep than CAMH. There

was no way to define search parameters regarding publishing date or peer reviewed. This search simply demonstrates the topics for which the vast majority of available information lies.

Table 2

Comparison of Online Open Access Literature Available

	Trauma	Sleep	Anxiety	ADHD	FASD	(fetal alcohol)	Microbiome
CAMH	40+	1	40+	6	7	7	0
CCPA	40+	37	40+	3	1	2	1

The 7 results for FASD and (fetal alcohol) on the CAMH website were the same articles.

CanFASD, being specific to FASD research, not surprisingly, had more academic research available. However, a search on this website yielded articles proclaiming the lack of research available. Anderson, et al (2017) state that “[a]lthough the relationship between psychiatric risk and FASD is well established, the mental health system has generally not embraced the disorder (p. 3).” Further, “[t]he currently poorly understood interactions of genetic and environmental influences to the exposure of varying levels of alcohol exposure in utero can also confound the process for diagnosing mental disorders in this population (p. 3).”

Brown et al. (2018) posit that “. . . there is a lack of mental health care professionals with expertise in FASD” (p. 14) and “. . . FASD is highly comorbid with trauma, substance use, sleep concerns, and other mental and developmental disorders (p. 15).” Brown et al. see a collaborative approach to FASD:

Although there is no standardized set of treatment techniques and strategies that can cure a life course persistent disorder like FASD, the key to maximizing outcomes for clients with FASD lies in treating each individual’s unique risks and needs in an integrated service delivery framework. This requires forging a network of cooperation,

collaboration, and consistency among the different professionals and caregivers involved in the client's life. (p. 16)

The Alberta Centre for Child, Family and Community Research (2016) summarize their clinical research gaps:

Future research should explore whether health, mental health, social services, and education are accessible and meeting needs of individuals and families affected by FASD. There also remains a lack of follow-up research conducted in adults with FASD or PAE that requires further attention. (p. 6)

Badry and Harding (2020) echo these findings: "Interdisciplinary, collaborative, systems-based, multi-level approaches are needed to support children and youth with FASD who often have many professionals involved in their lives" (p. 5).

Direction of FASD Research in BC

It seems there has been growing interest and funding for research in the FASD population over the last several years; in particular, in the areas of diagnosis, assessment, and prevention. I attended four International FASD conferences in Vancouver as a Key Worker. In the even years, the focus is on adolescents and adults with FASD, while in the odd years, the focus is on children living with FASD. While I appreciated the emphasis on scientific discovery, the tangible piece I took back to my community and families were the conversations with other Key Workers and adults with FASD attending the conference: digging deeper into the lived experience.

The University of British Columbia has been hosting conferences on FASD for the last sixteen years. The top area of interest, in terms of number of sessions provided at these conferences through the years, is in front-line programming; essentially, sharing what is already being done. These sessions, as shown in Table 3, speak to the importance of using a trauma lens,

Indigenous-specific programming, sensory needs, school readiness and interventions, family support, the Key Worker program, caring for the caregiver, behavioural strategies, and the lived experience, for example. At every conference there are also several sessions, sometimes full day pre-conference sessions, speaking to FASD and the law including over-representation and vulnerability of individuals with FASD, how prevention is utilized in the legal system, the ethical issues of neurodevelopmental impairment and determining culpability, and changing policy in the justice system to better reflect the disability.

Over the 16-year history of the International FASD conferences in Vancouver, many sessions have been dedicated to medical aspects including the ethics and resources of screening in family doctor's offices, treatment of pregnant women using substances, medication use, physical health issues, and nutrition: 22.7%. Scientific research into neurodevelopmental growth, biomarkers, animal research, 3D facial imaging, maternal drinking patterns, sleep, and the microbiome were most often presented in the plenary presentations as well as sessions: 20.2%. Mental health made up the fewest sessions, with counselling techniques being few and far between: 7.4%. The presenters in the counselling field predominantly relied on presentations and consultations to share their knowledge rather than studies or papers as limited information or research papers could be found from these presenters in the academic search. Legal aspects affecting youth and adults living with FASD also had a prominent place in the presentations including criminal justice advocates such as judges and probation issues, government policy, and the impact of colonisation such as disproportional representation of Indigenous people living with FASD in the criminal system: 19.5%. Finally, front-line programming included life stories, family support strategies, caregiver support programs, Aboriginal-focused programming, and community outreach: 30.2%.

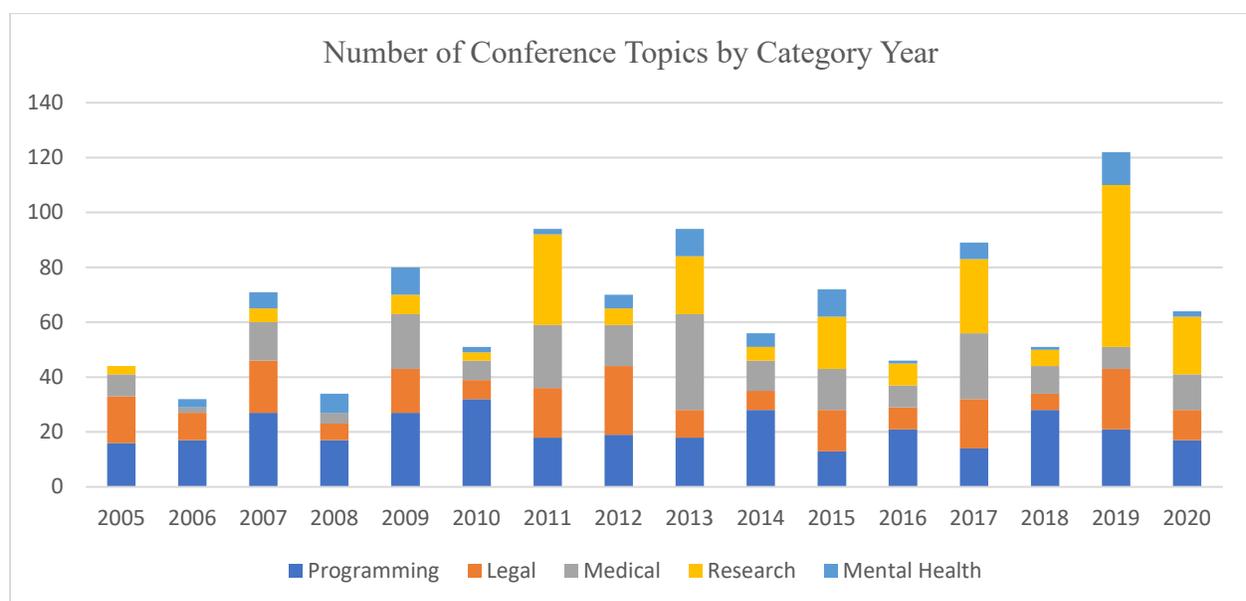
Table 3*UBC International FASD Conference Sessions by Type from 2005-2019*

Category	Type of Session	Number of Sessions Over 16 Years
Programming	Community & Key Workers	77
	Child & Youth: Strategies & Interventions	56
	Adult: Aging & Transition & Life Stories	45
	Family Support & Strategies	44
	Aboriginal: Community & Prevention & Intervention	37
	Child & Youth: School Intervention & Strategies	34
	MCFD & Child Welfare	16
	Care of the Caregiver	15
	Evaluation	9
	Total	333/30.2%
Legal	Justice & the Law & Homelessness & Housing	114
	Prevention & Media & Stigma	85
	Government & Policy	11
	Colonisation	3
	Economic Impact	2
	Total	215/19.5%
Medical	Ethics & Assessment & Diagnosis	141
	Biological Mothers: Addiction & Treatment & Infant	41
	Mortality	
	Screening	29
	Physical Health	26
	Medication	8
	Nutrition	6
	Total	251/22.7%
Research	Neuro Development & Sensory Functioning	71
	Biology & Epigenetics & Biomarkers	44
	Animals	43
	Maternal Drinking	32
	Community Programming	16
	Sleep	14
	Microbiome	3
	Total	223/20.2%
Mental Health	Attachment & PTSD & Grief/Loss	45
	Counselling Strategies & Techniques	16
	Behavioural Issues	21
	Total	82/7.4%

Figure 1 (below) demonstrates the increase in research in the last few years but a relatively stable presence of the four other categories from 2005-2020. Figure 1 also shows that in the odd years, where the focus is on children, research sessions have historically been more prominent; however, both the odd years and even years show an increase in presentations with research-based topics.

Figure 1

UBC International FASD Conference Topics by Category by Year



Figures 2 and 3 (below) provide insight into the focus of sessions over the last 16 years between child-focused conferences and youth- and adult-focused conferences respectively. For the child-focused conferences, research topics have increased consistently, and in the last year, 2019, increased dramatically, while the other conference topics have remained relatively stable. Mental health related topics have increased slightly for child-focused sessions while decreasing overall for youth and adults. Programming and focus on community have dominated the conference sessions from the beginning for youth- and adult-focused sessions.

Figure 2

UBC International FASD Conference Topics by Category in the Odd Years

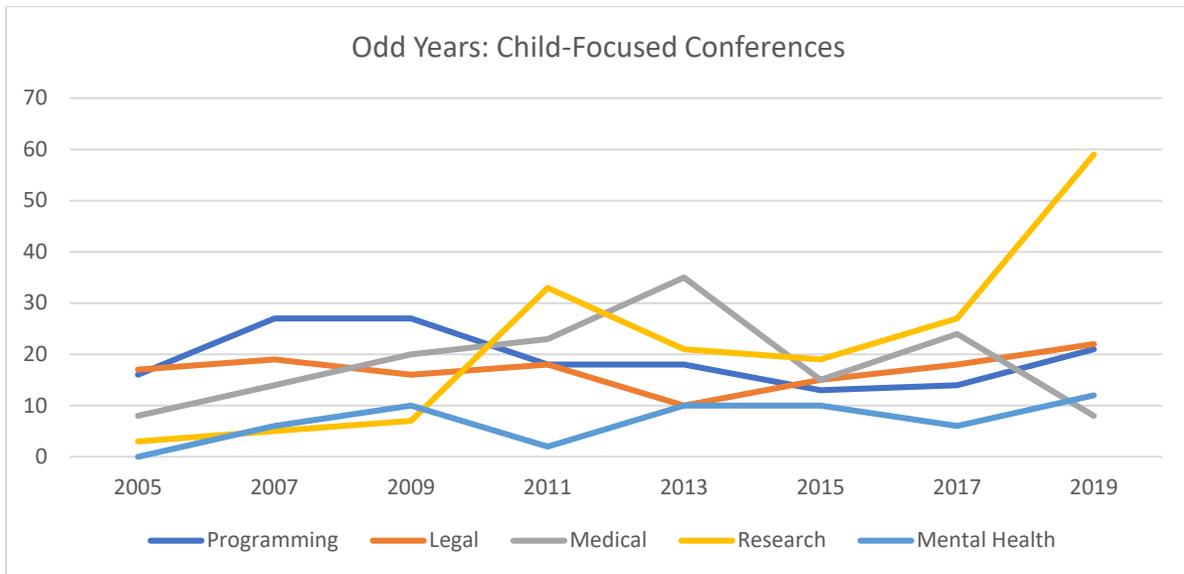
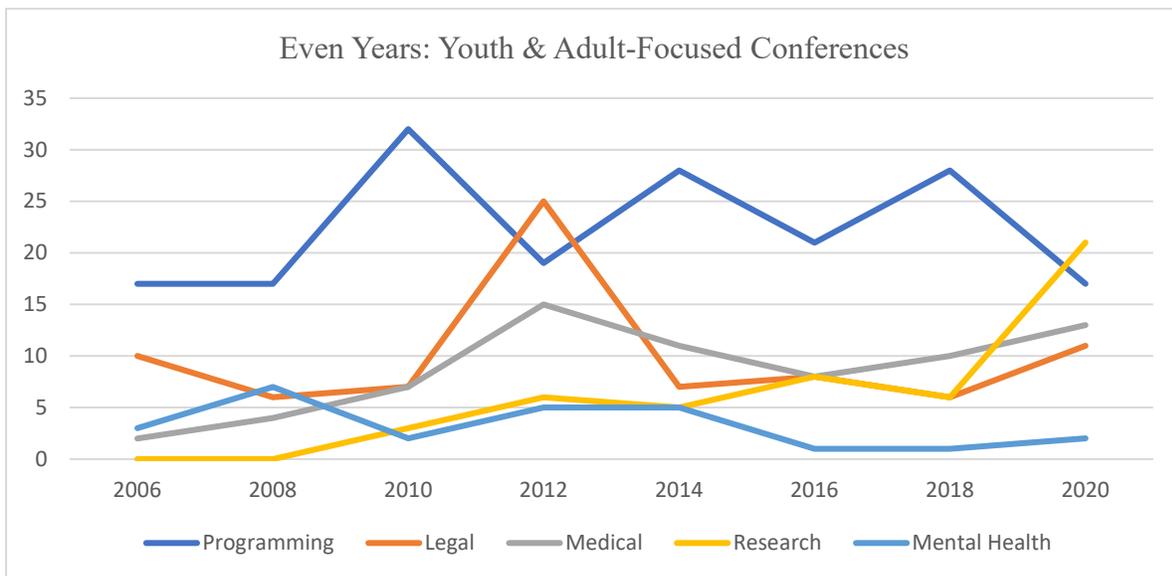


Figure 3

UBC International FASD Conference Topics by Category in the Even Years



Chapter 5: Discussion

In our story, the duck mother is cut away, forced away from her instincts. She is taunted for having a child who is different. She is divided emotionally, and as a result collapses, and withdraws her caring from the alien child. Although initially she tries to stand firm, the duckling's "otherness" begins to jeopardize the mother's safety in her own community, and she tucks her head and dives. (Estes, 1995, p.186)

The Community Concept

Choate and Badry (2019) speak to the growing social movement around FASD that echoes the disability movement: "Nothing about us without us" (2019, p. 37). The impact and influence of community plays a profound role in the discussion of mental health and counselling for the FASD population. The concept of community is a recurrent theme in this population, particularly for youths and adults; for example, the vast majority of topics at the research-based UBC International FASD conferences for youths and adults were presentations from front-line community workers with programs that had been designed and implemented by and with their community in mind, informed by people living with FASD. Community protects us and it stigmatizes us. The nature of this disability is such that an individual, and their family, requires the nurturing, protective support of a community. Paying attention to how an individual moves through this concept is vital to their success. The UBC International FASD conferences in Vancouver support a growing community of individuals with FASD who participate in and conduct research that is designed to inform scientists and front-line professionals.

The system of care can see children with FASD as a lot of work (Dubrovsky, 2015a). At the top of the list are the behavioural challenges, often the primary reason a caregiver (and/or teacher) seeks medical and developmental support. At the 8th International Conference on FASD

in Vancouver, British Columbia, Dr. Hanlon-Dearman (personal communication, March 9, 2019), a pediatrician certified in behavioural sleep medicine, paints a picture of a typical three-year-old child living with FASD who has been a restless sleeper since birth. The child's mother is a single parent who is supported by family and friends. Often a shift worker, the mother finds the child will not fall asleep until late, usually around 10pm when she gets home. There is often technology in the bedroom to "calm" the child, the child chews pajamas and blankets, rocks back and forth, and once asleep will waken in the night screaming. This child is aggressive and dysregulated during the day. As the child ages, they struggle to concentrate in school, they are frequently tired and restless. At about age 8, ADHD is often diagnosed and the child is put on a stimulant. At around 15 years of age, the youth continues to be tired during the day and has difficulty concentrating. The youth is up late at night, often playing videogames and texting friends, and struggles to settle. The youth has found marijuana helps relax him and enables him to sleep.

The high prevalence of chronic sleep issues is perhaps the reason why children with FASD struggle socially (Ipsiroglu et al., 2012); further, they tend to seek out other kids with similar impulse control issues and end up in trouble at school and in community (O'Neil, 2017). They do not adhere to rules, they cannot sit still, and they appear to develop problems with technology and substances easily and at a young age. In my experience, sometimes the police were involved to "deal" with children and youth because the staff or families were unable to mediate the situation. Not only is it traumatizing for all involved, it exposes the desperate lengths to which families and staff feel compelled to go in keeping the child and their peers safe. This is not a judgement on schools, support staff, family, or the children. In order to support a child, one must also listen to the support group around the child: the parents, extended family, and teachers.

How have their worlds shifted to accommodate this child? How many of them turn up thinking “here we go again” instead of looking forward to time spent together?

Frederick et al. (2017) speak to the concept of community as it pertains to individuals with psychiatric disabilities. The portrait painted through assessment of a child living with FASD radically changes over the lifespan as environmental, social, biological, and cognitive change and growth occur. I saw this in the parents. If the parent has a suspected FASD, they can be challenging to work with, too. The parent will miss appointments and not follow through on suggested behavioural strategies. I have worked with parents who unexpectedly drop off their kids at a relative’s house and leave town for a week because they were exhausted. Parents who wash dishes only when they run out of clean ones. Parents who cannot budget, cook, shop, clean, or do laundry. Parents who love their children but are unable to manage. Parents who cause front line professionals to constantly seek supervision regarding where their line is in the sand in their duty to report. It can be an ethical minefield. Morton Ninomiya (2015) posits that the child welfare system is organized, or designed, to remove children rather than support the family. For families living with FASD, the child-centric approach is actually damaging to the child. When we shift the responsibility for inclusion onto communities and individuals, we systemically avoid issues of mental health, stigma, racism, colonialism, and poverty (Frederick et al., 2017). When we fail to recognize the profound impacts of community on the FASD population we miss the negative (stigma and isolation) and positive (motivation and support) that are vital to how we walk alongside these individuals and their families.

New Directions (2018), a FASD family support, education, and counselling program in Winnipeg, Manitoba quotes a parent on their main page: “The Counsellor was really helpful in finding daycare for my child and summer programming, their support made a big difference in

my life, knowing they were always there to help.” Counselling for individuals living with FASD may look vastly different from talk therapy that starts and ends in an office.

Benefits and Limitations of Diagnosis

The diagnosis of FASD in British Columbia comes with a report of a detailed treatment plan including specific areas of cognitive functioning that require support. These reports are utilized in the school system, for example, and supported by educational assistants (EAs) and Special Education teachers as well as community outreach services such as FASD Key Workers. Most interventions are focused on self-regulation and behavioural support both in school (EAs) and in the home and community (Key Workers). However, this report is specific to the age and developmental stage of the child at diagnosis. The assessment, if initially done early on, is rarely repeated again in adolescence. If it is done very early, for example, before 5 years-of-age, the diagnosis might be *at risk* for developmental delay from alcohol exposure; it is up to the parent to remember to go through the referral process again at a later age to determine if the symptoms continue to suggest a FASD diagnosis is required.

In my experience, parents express great frustration with what the diagnosis of FASD itself affords a child in terms of supplemental support in the school system. A diagnosis of FASD on its own does not equate to funding for extra support, a limitation to accessing a stigmatizing diagnosis (for both mother and child) in the first place for many parents. Rather, a co-morbid diagnosis of a Moderate to Profound Intellectual Disability or Intensive Behaviour Interventions or Serious Mental Illness are required, by the school system in British Columbia, to qualify for additional services to a child in the classroom (Government of British Columbia, n.d.). In terms of adults, an individual with FASD may qualify for disability assistance; however, if there is an

audit of the disability funding at a later age, funding may be removed if the individual is deemed to be not affected by delayed cognitive functioning any more.

At issue is the inability to lock down how exposure in utero affects the child. Is FASD a physical or cognitive impairment? The answer is yes. Does exposure cause mental health issues or are they secondary? The answer is yes. Is FASD a medical or psychological impairment? The answer is yes.

Rural communities do not often have many services common to larger centres such as pediatricians, behavioural specialists, and diagnostic teams needed for diagnosis and sometimes treatment itself. Complex factors contribute to why children with a suspected FASD fall through the cracks in the early years. Stigma is a big reason. Fear of ministry involvement is another. Mis-diagnosis, commonly ADHD, contributes to why professionals do not look further into the etiology of presenting symptoms. When the child starts kindergarten, time is spent acclimating the child into the program. Internal assessments of behavioural modification begin if the child struggles with externalized behaviour such as impulse control and sitting still. These children, typically boys, see referrals and intervention sooner. For children who internalize behaviour, typically girls, intervention may not come until much later, usually high school, when the disability shows up as mental health issues such as depression, anxiety, and sometimes suicidality. Research suggests that parents commonly perceive health care professionals and service providers as “unaware of the signs and symptoms associated with FASD” (Coons et al., 2017, p. 77). Coons et al. (2017) point out that two Canadian studies indicate only 60% of health care providers surveyed were able to accurately identify the correct information regarding a diagnosis of fetal alcohol syndrome (FAS).

Assessment is only done in major urban centres such as Sunny Hill Children's Hospital in Vancouver. If you live within easy traveling distance, testing can be done over a period of months with time in between each session. Anyone from smaller rural communities must travel to the assessment centre and stay up to a week to access all testing in quick order. In British Columbia, there is financial support for transportation, accommodation, and food depending on individual family eligibility. This process, while helpful for the child regarding outcomes, can also be a stressful time for the family, particularly if transportation and/or living with poverty are barriers. There often is a reliance on public transport, taxis, and take-out food as well as the consideration of needing to pay for things upfront and waiting for reimbursement. Being away from family members, other children, and support systems can be difficult, too. It is not uncommon that families will exhaust funds while in Vancouver and require emergency funds to get them home.

Accessing Counselling

Adults

It is fair to say that when counselling women who live with poverty and who have biological children diagnosed with FASD, assuming the presence of trauma and violence is wise until you know differently; that is, a FASD-lens which includes the concept of a trauma-lens. Unilateral violence is not "intimate" nor "sexual". When we choose to believe that no woman intends harm on her unborn child and that every woman resists violence, we open the door to a deep compassionate well of acceptance and dignity. We have seen a shift in professional approaches and social discourse from understanding addictions through a harm reduction lens instead of abstinence. So, too, must we understand FASD from the ethical perspective of woman's rights rather than prevention which focuses on primarily protecting the fetus. When we

focus on protecting the fetus, we negate the dominant role abusive partners play in women's substance use.

Access to counselling for individuals living with poverty, affected by FASD, is challenging at best. First, they have to recognize a need for counselling, then have a desire to access it. Often the adult is mandated to counselling to maintain custody of their child or referred by a family doctor. Barriers include where those adults are able to get counselling. In my community, non-Aboriginal mandated clients and those reliant on the system to pay for counselling have one choice: the Mental Health and Substance Use (MHSU) department at the hospital. Clients are not able to choose their counsellor, the wait list can be months, and visits are capped at 8 even though it is widely recognized that people living with FASD require life-long support. The BC College of Family Physicians (2018) recommends integrating mental health and substance use into home-like practices and community health centres to address the stigma of hospital-based mental health. While counsellors, in general, have access to information and strategies for working with clients with FASD, very few counsellors specialize in it; there are only a small handful in BC. Anderson et al. (2017) speak to the lack of FASD-informed considerations in the Canadian National Strategy for Mental Health:

Currently, the risk is that the care provided will remain substandard until health clinicians recognize the uniqueness inherent in the large population of those with the complicating neurocognitive differences of FASD comorbid with an additional mental disorder diagnosis. Inadequate services leading to ineffective measures increase the cost of care and add to frustration among clinicians who struggle to best address the needs of their clients. (p. 73)

Natascha Lawrence (personal communication, March 26, 2020), one of the few registered clinical counsellors in Vancouver, BC that specializes in neurodiversities in children, youth, and adults, including FASD, shared her perspective that the focus of research is moving away from mental health and more towards medical research. What clients have shared with her is that typical counselling sessions are reliant on talk therapy which requires receptive language and short-term memory, both of which the FASD population, in particular, struggle with. Instead, Lawrence relies on what she termed “the wisdom in the body”. While there have been several mental health professionals who have shared wisdom such as this at the International conferences in Vancouver, little is actually available through academic sources regarding these approaches, unlike the plethora of written and published studies on topics such as diagnosis, prevention, and justice.

Children

Pei et al. (2017) contend that while there is a great deal of intervention research available, literature examining the efficacy of those interventions is limited as is evaluation of consistency in programming in different jurisdictions. Clinicians are typically reliant on anecdotal reports and “clinical wisdom” in making treatment decisions (Pei et al., 2017, p. 177). Rowbottom (2012) echoes strategies utilized and discussed by Key Workers and the odd clinician; for example, sequencing events is difficult. Often children are accused of lying where working memory barriers are at play. Teaching children strategies for remembering is helpful. Adjusting the approach to the appropriate developmental and emotional level is necessary: One cannot assume it relates to chronological age. The use of visual aids is helpful, as is not talking too much, involving caregivers, and above all, focusing on the relationship. Supporting families to

speak with their family doctors increases awareness of the importance of understanding the multifaceted levels of FASD such as the nature of sleep and FASD.

Himmelreich (n.d.) advises professionals and caregivers to not get lost in the behaviour. Where most see defiance and opposition, compassionate care includes understanding resistance and social response as well as the impact/influence of trauma, sleep deprivation, and behavioural implications from an under-developed microbiome, for example. It is unlikely the child is in therapy for FASD; rather, the child is there because the behaviour is aggressive, curious, and/or harmful with all the underlying, complex biopsychosocial layers. Establishing a relationship with the parent and involving the parent in the process, as needed, supports successful outcomes; a child's confidentiality can be maintained while working on family goals. Knowing what services are available in the community is helpful for the family. Has the parent connected with a Key Worker? If the parent also has a diagnosed or suspected FASD, appointment reminders help ensure the parent is prepared. The parent is the best ally; they are doing the best they can.

Accessing counselling can be difficult; in my community, if you cannot afford a counsellor, Child and Youth Mental Health offer free counselling. Like MHSU, there are limited sessions, you cannot choose your counsellor, and there is a long wait list. Sessions are in a small office and are reliant on talk therapy with some access to play or art therapy.

Rowbottom (2012) discovered that research suggests cognitive behavioural therapy (CBT) for individuals with intellectual disabilities is effective. However, knowing that program evaluations are lacking in this area, I would ask what the evidence is. Rowbottom points out that in order for CBT to be useful, individuals must be able to draw connections between thoughts and feelings, an area Rowbottom suggests those with intellectual disabilities typically struggle with.

Ethical Considerations

Informed consent with the FASD population is not a one-time-act, but ongoing throughout the process. Informed consent demands helping the client understand precisely what the treatment entails. As the Canadian Counselling and Psychotherapy Association (2015) identifies, a counsellor's ethical responsibility is to ensure information is presented in a way that is understandable to the client. Just because the individual can recite the rules, does not mean comprehension follows. This is true for the child and often the parent in many cases as well. Of particular importance is outlining a counsellor's responsibility to report harm. Many of these parents have had extensive ministry involvement themselves and/or their children; being transparent about what constitutes harm is vital in gaining trust. Similar to the consent conversation, continuous conversations regarding what is ethically reportable are often needed. Helping clients understand their rights as well as what constitutes ethical behaviour can support the client in making better choices for themselves and their children.

A woman's right to drink alcohol, a legal substance, is also an ethical consideration. Research conclusions default to an abstinence-based model because studies are based on observational and animal model data. Researchers just cannot say, for certain, how much or when damage may be occurring during the course of the pregnancy. Complicating factors such as the impact of trauma and stress on pregnancy also make consumption recommendations complex. Rather than a focus on alcohol use, we can understand the lived experience and advocate for protective factors such as nutrition, outreach, and health care.

General Practice Recommendations

Drawing from Rutman (2016) and Hubberstey et al. (2015), the following universal recommendations for FASD-informed practice are summarized. Rutman stresses that above all,

“it is the system, program, and/or service providers who need to make modifications rather than the person with FASD” (p. 16). Rutman, together with several other researchers have actively engaged in creating evaluation frameworks for FASD programming; for example, Hubberstey et al. created three visual maps. These maps represent FASD prevention programs, FASD support programs, and FASD programs in Aboriginal communities; the study was Canada-wide.

Rutman, together with Hubberstey et al., contend that successful counselling includes:

- The provision of a space without judgment, misunderstanding or labeling to foster a trustworthy relationship. Many of these individuals, particularly mothers, are hypervigilant for this. The phrases “let me get this right,” “when you say this, this is what I am hearing,” or “it sounds like you are saying” provide opportunities for the individual to hear their thoughts and take the time to find the right words to describe and explore them.
- Use of first-person language, such as a person living with FASD rather than a FASD person. Externalization of the concept “FASD” can be empowering. In the world of autism, self-advocates prefer “autistic individual” to “individual with autism”, considering autism to be a pride-worthy part of their identity (Harte, 2019). FASD is rarely considered a “pride-worthy” aspect of an individual’s identity.
- Use of clear, concise language with one step or instruction at a time. Too many questions can quickly overwhelm an individual.
- Support with scheduling or appointment reminders may be needed. Visual reminders such as calendars or photo/picture cues can be helpful. Attendance difficulties, lateness or missed appointments, may not be lack of interest; rather, simply forgotten or misunderstood. Best practice is to ensure the appointments are at the same time every

week on the same day. When counselling sessions come to an end, it can be important to discuss what the individual will do with that time slot moving forward and to support achievable plans with the individual.

- A trustworthy relationship will lay the foundation to ensure understanding and literacy level. Checking in periodically during a session to gauge comprehension level will avoid assumptions of understanding.
- Practice that enables modeling and coaching, rather than only talking, can be supportive. A hands-on approach can be helpful; for example, engaging in the desired activity with the individual to promote experiential learning. An individual with FASD may not be able to generalize from one situation to the next. Generally speaking, if you teach someone to cross the street at Main and 6th, you may need to repeat the teaching process to cross at Main and 7th.
- Goals, objectives, or tasks can be a useful measure of progress; however, they will need to be broken down into manageable steps. Sometimes you might need to further break down one of the steps if it is proving a barrier rather than a learning tool.

In his search for meaning, Viktor Frankl (1959) proposed the concept of the space in between stimulus and response; what we see as impulsive, anti-social behaviour is often the result of a barrier to access that space and respond freely in a way that empowers agency in the individual. Essentially, the practice guidelines proposed by Rutman (2016) and Hubberstey et al. (2015) enable that *space in between*.

Personal Reflection

Last year I participated in a community action evaluation project that involved seven communities across Canada (Underwood & Ceolin, 2019). The aim was to develop strategies

within programs to become more inclusive of children with a wide array of diverse abilities (or *diversabilities*, as is commonly used). The four main results of this program were that accessing supports and services is a lot of work for families; disability services are predicated on a medical model which privileges diagnosis as a gatekeeper to services; service availability and priority are geopolitical; and, parents are responsible for multiple service access making inclusion across the spectrum of services rare. Underwood et al. (2019) propose that institutional mapping can be a useful professional development tool to fully understand the institutional processes that are a social response to disability.

These maps are also a useful tool to represent the work of families in navigating this institutional process. The maps highlight a family's relationships and actions through phone calls, emails, appointments, and paperwork. The programs and services that identify, document, and diagnose complex developmental behavioural conditions, like FASD, require a great deal of referrals and institutional processing let alone organization and motivation from parents who may have a cognitive disability themselves. Not to mention, for those families that live with poverty, they must also navigate the social welfare system, food banks, seasonal funding programs like Christmas hampers, community programs that offer funding for kids' activities, public transportation, safe housing, sustainable employment, and disability funding.

When a child is diagnosed at Sunny Hill Children's Hospital, the resulting comprehensive report will often identify and recommend beneficial services and supports including mental health. In their study, Pei et al. (2017) contend that while the majority of families report being successful at finding recommended interventions, there are no investigations into which specific categories of interventions are being accessed or how effective they are. How effective are the links between clinical recommendation and service access? There

is a strong relationship between mental health issues and FASD; this is often a recommendation by diagnostic teams. Anderson et al. (2017) argue that “actively acknowledging FASD in the strategies we use to approach mental wellness will have trickle-down benefits for the comprehensiveness and future advancements of our current mental health system” (p. 75). Are we, as clinical counsellors, actually seeing what we think we are seeing?

Conclusion

At the heart, FASD is infused with cultural and social attitudes towards women and drinking. All too often, the issue is presented as the rights of the woman versus the fetus; a spectrum of socially constructed versions of personal choice to a paternalistic oppression and everything in between. Socially we label the type of woman who drinks and why; from the woman exercising her right to self-care (e.g. have a glass of wine) to the assumptions of a woman intending harm on her baby. It is perhaps ironic that our socially created assumptions lead to isolation of the individual. By excluding the impacts and influences of community on individual reasons why women drink during pregnancy, we inadvertently, and sometimes intentionally, remove community responsibility and accountability in the prevention and treatment of FASD. Looking beyond the choice to drink or not (which assumes will power is all that is needed) invites a wider spectrum of solutions that acknowledges a woman’s rights and agency rather than simplifying it to a question of choice.

The implications for counselling practice from emergent research on assessment and intervention with behavioural challenges in children with a diagnosed or suspected FASD are reliant on how we help an individual (and sometimes their family, as well) make sense of their life circumstances. The biopsychosocial model of care can benefit from a deeper understanding of the impact of the biological on the psychological. In particular, this study has demonstrated

that when the microbiome is negatively impacted by teratogenic agents like alcohol, as well as by trauma, behaviour is impacted through gut-brain connections. Chronic sleep deprivation from deficiencies in iron typical in the FASD population is also a determinant of how well a person is able to function behaviourally during the day. This also helps explain why predicting the life-trajectory of a person diagnosed with FASD is so difficult; left untreated, microbiome and sleep deficiencies can compound with negative social responses to perceived anti-social behaviour. So-called deviant behaviours are assumed, expected, and legitimized as “illness” (Morton Ninomiya, 2015) further limiting individual agency.

This study has shown that research on counselling approaches, theories, and strategies for those living with FASD is limited with much of the existing literature focused on siloed areas of mental health such as trauma, ADHD, and anxiety in the general population. Given the staggering percentage of people living with FASD who also have comorbid mental health diagnoses, why is there not more research-based, academic literature related to clinical counselling-based resources outside of direct FASD-based information sites? It has been shown that ADHD shows up differently in those with and without FASD; what are the implications for other common mental health diagnoses, then, such as anxiety and trauma? What is the collective professional ethical responsibility to getting these diagnoses and treatment approaches right, given that this population continues to struggle? Finally, research on the microbiome and sleep in the FASD population is still emerging and awaiting further connections to the practice of clinical counselling.

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