

The Lived Experience of Foster Parents in Placing Children in Care on Medication for the  
Management of Behaviors Associated with Fetal Alcohol Spectrum Disorder (FASD)

By

Simone Richard

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## ACKNOWLEDGEMENTS

My name is Simone Richard. I am Anishinaabe Ikwé, originating from the Métis community of Camperville, Manitoba. I began my education as an early childhood/school age educator in 1984, and worked in a daycare for 20 years. During those years, I started working part time toward my Bachelor of Social Work (BSW) degree, and graduated from the University of Manitoba in 2008.

I have been employed by MacDonald Youth Services (MYS) since 1988 as a respite/support worker, and also as a foster parent. After graduating with my BSW, I became a direct service worker for an Aboriginal Child and Family Services (CFS) agency, and continue to work in child welfare to date.

It is those beginnings that have had the most impact on my learning. I value the children that I have known and learnt from, as they have influenced my learning. It is through their stories that have inspired my dedication to ideas behind this thesis.

In my work in Child and Family Services, I had met a grandmother whose grandchild was in our care. I was bringing her home for a weekend family visit, and brought along her medications [Dexedrine risperidone]. When I picked her up after the weekend visit, the grandmother said to me,

*You tell me my granddaughter has a brain impairment [FASD], yet you [the agency] have placed her on these strong medicines. I was reading about them, and it says you should not take them if you are under 12, yet my granddaughter is eight years old. If I am not defending my granddaughter, who is going to defend her?*

It was her words that inspired my journey through this thesis. In sharing in the stories of the foster parents, and listening to what they are saying about their own journeys when medicating their foster children, it is hoped that individuals who are in a position to make changes will listen to what they say about which interventions are working and which are not. Also, to further the learning and knowledge to those who will take the torch and continue on...

I dedicate this thesis to all those children I have known and loved, to my nieces and nephews, my mother, my family and my children. May you follow your dreams, and aspire higher...I love you.

Special acknowledgement to my advisor Dr. Cathy Rocke, thank you for your continual encouragement and support, thank you to my committee members, Dr. Don Fuchs, and Dr. Roberta Woodgate. You are all trailblazers' in your own ranking, thank you for accepting and being so patient with me on this learning path. Lastly, I want to say thank you to Teresa, as she had been there alongside of me and tutored me through the process. All the Best!

## LIST OF ABBREVIATIONS

<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>ARBD</b>	Alcohol-Related Birth Defects
<b>ARND</b>	Alcohol-Related Neurodevelopmental Disorders
<b>AWL</b>	Alcohol Warning Labels
<b>AS</b>	Asperger's Syndrome
<b>ASD</b>	Autism Spectrum Disorder
<b>CDC</b>	Center for Disease Control
<b>CFS</b>	Child and Family Services
<b>CIFASD</b>	Collaborative Initiative on Fetal Alcohol Spectrum Disorders
<b>CNS</b>	Central Nervous System
<b>FAE</b>	Fetal Alcohol Effects
<b>FAS</b>	Fetal Alcohol Syndrome
<b>FASD</b>	Fetal Alcohol Spectrum Disorders
<b>HPA</b>	Hypothalamic Pituitary Adrenal Axis
<b>IOM</b>	Institute of Medicine
<b>IQ</b>	Intelligence Quotient
<b>MRI</b>	Magnetic Resonance Imaging
<b>ND-PAE</b>	Neurobehavioral Disorder with Prenatal Alcohol Exposure
<b>OCD</b>	Obsessive Compulsive Disorder
<b>PAE</b>	Prenatal Alcohol Exposure
<b>pFAS</b>	Partial Fetal Alcohol Syndrome
<b>US</b>	United states of America

## ABSTRACT

First Nations children, in the care of Child and Family Services in Manitoba are often placed on medication for the management of behaviours associated with Fetal Alcohol Spectrum Disorder, or its comorbid condition Attention Deficit Hyperactivity Disorder.

This study was conducted using a qualitative research design with exploratory qualitative semi-structured interviews to hear the voices of caregiver(s). Semi-structured qualitative interviews were conducted with 15 participants, between January and May of 2017.

A qualitative exploratory study was used to analyze the findings, looking for emerging themes in the data. Five thematic concepts emerged; The process for determining the need for medication; the influence of the school system on suggesting the need for medication; the use of medication and other interventions; dependency created by medication and finally; outcomes of children in care with FASD.

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## INTRODUCTION

Many Aboriginal children, in the care of child welfare agencies, are being placed on medications for behaviors attributed to FASD (Timimi & Taylor, 2004), or its comorbid conditions; such as attention deficit hyperactivity disorder (ADHD) (Rasmussen et al., 2010). This thesis examines the lived experience of foster parents in placing children in care on medication for the management of behaviors associated with fetal alcohol spectrum disorder (FASD). For the purposes of this thesis the terms Aboriginal, First Nations, and Indigenous are used interchangeably to identify the first peoples of Canada. These peoples include, but are not limited to the variant Aboriginal groups (e.g., Ojibway, Cree), the Métis and the Inuit. These children and their guardians often have a limited say in the medicalization process (Leslie, Raghavan, Hurley, Zhang, & Landsverk, 2011) and appears to be no clear path as to what individuals or agencies are responsible for initiating, administering and tracking regarding the use of the medications (Naylor et al., 2007).

At present, children with FASD are commonly placed on a schedule of psychostimulants to manage their condition. However, neither this course of medications or others such as Adderall<sup>®</sup> or Dexadrin<sup>®</sup> have been proven by any scientific evidence to aid with the management of FASD or ADHD, as there have been no long term studies to address their effects on children (O'Malley & Storoz, 2003). Timimi and Taylor (2004) are critical of the dependency that children have on both the medical system and the medications they are placed on, when pharmaceuticals are used as the main intervention for children with FASD or ADHD. They reinforce that, we are damaging children by placing them on medications that are “highly addictive” that may in fact produce negative effects in the long run (Timimi & Taylor, 2004, p. 8). Various authors express that medications, such as Ritalin and Adderall, used to treat

disorders such as FASD and ADHD can be potentially addictive to highly addictive for the children that use them (Morris, 2016; Timimi, 2004), and that the neurochemical effects of drugs such as Ritalin can be comparable to those seen with cocaine.

Although there needs to be the option of medication, it cannot be the only solution and one way to provide different options is increased knowledge. Multiple authors state that there needs to be greater understanding of FASD within child welfare systems, and one way to develop this is to listen to parents of children with the disorder to glean from their experience that which experiential knowledge provides (Jones, 2003; Olson, Oti, Gelo, & Beck, 2009). This increased knowledge will benefit two fold; agencies will obtain the knowledge which they need to better serve that vulnerable population, while parents will feel that their expertise is valued and feel respected (Coons, 2013). Learning from those that came before, that have had similar experiences and have had to work through similar struggles can bring a wealth of knowledge for children and families that are facing problems on a daily basis.

This study examined the process that occurs when children are placed on medications for FASD or its related conditions, using exploratory qualitative semi-structured interviews to hear the voices of the caregiver(s). It was the hope, that through this research their voices would be heard, and that their expertise will help to understand and implement changes in policy and services to better meet their needs, as well as, those that follow.

## **CHAPTER ONE: Literature Review**

### **Introduction**

First Nation children are overrepresented in Child and Family Services (CFS) in Manitoba (Blackstock, 2009; Fuchs, Burnside, Marchenski & Mudry, 2009). Children come to the attention of CFS agencies for many different reasons, however there are often some common factors, such as; family historical trauma (McKenzie & Morrissette, 2003), parental abuse (Hellemans, Sliwowska, Verma & Weinberg, 2010): , alcohol or drug addictions (Fuchs et al., 2009). High rates of alcohol addiction have led to children being born into the umbrella term, Fetal Alcohol Spectrum Disorders (FASD) (Bennett, 2009), often leading to life-long challenges (Sanders & Buck (2010).

Fuchs, Burnside, Marchenski and Mudry (2005) conducted a study to determine the prevalence of different types of disabilities in the child welfare system in Manitoba. Of the children with a disability, they found that 34.2% of children had a diagnosis of FASD, or 11.3% of the children in CFS as a whole (Fuchs et al., 2005). Chatterley-Gonzalez (2010) speaks to the need for social workers to be prepared by stating, “[t]he high number of children coming into care due to parent’s drinking and drug use should alert us to the possibility that we are working with children and families affected by FASD” (p.95).

Although FASD may be a fairly recent term, the effects of alcohol consumption on unborn children have been noted throughout the centuries. This chapter examines numerous aspects of the disorder, including; historical beginnings; past and present methods of diagnosis; risk factors and development of FASD; secondary disabilities and co-morbid disorders; preventions; interventions; parenting and the role of social workers. By tracing back the origins of the disorder, to what we know about FASD in present day, we begin to obtain an

understanding of how to provide treatment and support for children affected by the disorder and those families who are taking care of them.

### **History of FASD**

Throughout history, there have been basic observations of children with FASD, although there were no formalities in their diagnoses. Observers in ancient times believed that children born of parents, who were under the influence of alcohol at the time of conception, would produce children with damage (Calhoun & Warren, 2007). Even the great philosopher Aristotle wrote that women who were drunken and foolhardy would mother children who would display similar characteristics. These thoughts continued to be so pervasive that the Carthaginians strongly held to a tradition ensuring the prohibition of drinking on the wedding night of recent nuptials, as they believed there to be a link between drinking alcohol and poor birth outcomes (Calhoun & Warren, 2007). This idea can also be found in the Old Testament, “now see to it that you drink no wine or other fermented drink and do not eat anything unclean, because you will conceive and give birth to a son” (Judges 13:4-5, New International Version).

As society began to change so did the perspectives on the acceptability of alcohol consumption. Those changes in societal standards were a possible catalyst to increased rates of female drinking.

The new models of life, modifying cultural tradition and drinking patterns, led to an increase of the spread of alcohol damage. Women are more affected by these lifestyle modifications, with increased risk for their well-being. Social acceptance of female drinking is low in some cultural contexts, and female drinking affects more than male drinking the life and health of the family (Mancinelli, Ceccanti & Laviola, 2006, p.165).

During the period of 1720 to 1750, the shadow of the gin epidemic fell over London when new distillation technologies were brought in from the Netherlands. This change in technology increased the supply of low cost gin which led to higher alcohol intake for

individuals who had not had the financial means to do so in the past. This excessive intake did not go unnoticed and became a major topic of debate, resulting in the London College of Physicians presenting their observations to the London House of Commons (Warren & Hewitt, 2009). The Royal College of Physicians of London, based on their observations, concluded in 1726 that children who were born to alcoholic mothers were “weak, feeble, and distempered children, who must be instead of an advantage and strength, a charge to their Country” (as cited in Calhoun & Warren, 2007, p.169). The physicians also regarded the children with this affliction to appear older than their chronological age (Goodacre, 1965 cited in Calhoun and Warren, 2007).

Burd, Cotsonas-Hassler, Martsof, and Kerbeshian (2003) indicated that these associations between excess alcohol consumption and poor birth outcomes were not limited to London as physicians in Dundee, Scotland were soon reporting similar results. The observations by Templeton (1892) found 258 deaths of infants which could be attributed to maternal alcoholism during pregnancy (Burd et al., 2003). Further, in 1899 in Edinburgh, observations were made of children born to incarcerated women. The overall observations indicated that more than 50% of the children born to these women were either stillborn or died before their second birthday, the rates of alcohol abuse by one or both parents were in excess of 61% (Sullivan, 1899). Sullivan (1899) further states that women who continued to drink heavily during their pregnancy were poisonous, not only to their children but also to society as a whole, as if their children survived they would become a “burden or a danger to society” (p. 282).

It was not until over half a century later in 1968 that observations by French researchers would result in one of the most prominent studies in the topic area (Lemoine, Harousseau, Borteryu & Menuet, 1968/2003). This foundational piece of research went unnoticed at first as it

was written in French and submitted to a small journal, however today it is cited as one of the pioneering works in its field (Warren & Hewitt, 2009). One of those papers included a dissertation, written by Jaqueline Rouquette in 1957, examining the effects that maternal drinking had on infant physical development (Barrison, Waterson & Murray-Lyon, 1985).

It was in the 1970s that a real explosion of research began to emerge in the area of alcohol effects on newborn babies. Three papers from the Washington School of Medicine in Seattle were published in the *Lancet* and would later become the forerunners in naming the condition (Jones et al., 1973; Jones & Smith, 1973, Jones et al., 1974). Although their first article provided a “detailed case report of three Native American, three black and two white children” (Calhoun & Warren, 2007, p.169) who had been born of alcoholic mothers, it wasn’t until their second venture into the area that produced the term which we now use today to describe this disorder - Fetal Alcohol Syndrome (Calhoun & Warren, 2007). The second article outlined three more cases of children born with “alcohol-related birth defects” which provided the needed foundation for the term of FAS (Calhoun & Warren, 2007, p.169). Their third article (Jones et al., 1974), a retrospective review of patient charts, centred on the identification of the teratological<sup>1</sup> effects of alcohol on fetal development.

The knowledge transfer from these articles was significant as it allowed for physicians to recognize the traits of the disorder and diagnose new cases. This produced a flood of further study in the area, resulting in reports and case studies examining the interaction between alcohol and birth defects, as well as secondary factors, such as poor nutrition or smoking, which contributed to the deterioration of their well-being. This increased knowledge of secondary contributing factors may have advanced the understanding in the field; however it set up a quandary as well. Such as, were the birth deficits a direct result of alcohol or could they be the

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<sup>1</sup> Teratological refers to abnormal formation or development. Merriam-Webster online. (2015).

outcome of one of the secondary factors instead (Warren & Hewitt, 2009)? The authors further note that “[t]he answer to these questions required the undertaking of animal and epidemiological research and a funding agency to support that research” (Warren & Hewitt, 2009, p.173).

Research conducted by the National Institute on Alcohol Abuse and Alcoholism examined the effects which teratogenesis had on animals (i.e., dogs, rodents and primates), observing that the same deficits which were reported in human children could be seen in them as well. This was a profound finding as confounding variables could be eliminated through additional control in the research and the effects of alcohol consumption on the fetus could be attributed more as a causal factor (Warren & Hewitt, 2009).

Inevitably it was due to this increase of research which led to the understanding that children diagnosed with FAS did not all fit into the same category of disorder, and thus a continuum of severity needed to be established to allow for the distinction of children with different levels of effect; from this, the term Fetal Alcohol Effects (FAE) was born (Calhoun & Warren, 2007). However, even with the positive moves which had occurred in the field, a problem was found with the vagueness of the term FAE. Aase, Jones and Clarren (1995) state that “Fetal alcohol effect (FAE) is inappropriately applied to children with nonspecific problems or abnormalities whose mothers may have drunk alcohol during pregnancy” (p.1). They add that the term, FAE, be abolished as its usage became commonplace and lost its accuracy, in that it was being used to even label symptoms that may or may not have been due to pre-natal alcohol exposure (Aase et al., 1995).

Furthermore, even though the term FAE was created to be used in everyday language, not one of clinical diagnoses, it was adopted into the ranks of clinicians and soon became the basis

for children obtaining educational and social supports (Hoyme et al., 2005). A diagnosis of FASD thus often became the sole criterion of assessment, resulting in similar symptoms from other medical conditions such as autism or Williams syndrome<sup>2</sup> not even being considered as a possibility. The vagueness of the classification, combined with its overuse as a threshold for obtaining services, created the realization for many researchers that the term FAE had to be changed (Calhoun & Warren, 2007).

The objections to the term ultimately resulted in 1996 the Institute of Medicine (IOM), convening a committee to create new classifications for the spectrum of disorders associated with exposure to alcohol in utero (Calhoun & Warren, 2007). Their result was a five category classification system, including “FAS with and without a confirmed history of alcohol exposure, partial FAS, [alcohol-related birth defects] ARBD, and alcohol-related neurodevelopmental disorders (ARND)” (Calhoun & Warren, 2007, p.169). Critiques soon surfaced about the classification system, stating that the categories were too vague with no assessment guidelines; they captured no background assessment of the child’s genetic history or family; and the definitions for alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) were not practical for clinical use in their current form (Hoyme et al., 2005).

Astley and Clarren (2000) created a diagnostic tool which would be more objective in its determination of FASD than the prior methods being used. Their tool, named the 4-Digit Diagnostic Code, “reflect the magnitude of expression of the four key diagnostic features of FAS in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) central nervous system damage/dysfunction, and (4) gestational alcohol exposure” (p.400). Children suspected

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<sup>2</sup> Williams syndrome (WS); a condition that a person is born with, that affects both sexes in every culture. The characteristics associated with the disease include; a heightened sense of music ability, very social personalities and high verbal acuity. Cardiovascular problems, developmental delays, and learning deficits are also often part of the condition.



of falling under the spectrum of disorders are assessed to determine the degree to which they may or may not have the disorder based on a four point scale, where (1) indicates the absence of a characteristic and (4) a full presentation. The four criteria are then used to create a four digit code which will assert them into one of nine diagnostic outcomes (Hoyme et al., 2005). Chudley et al. (2005) supports that use of the 4-Digit Diagnostic Code, but he also recommends in addition the use of multidisciplinary team for early intervention and support for both the individual with FAS and the family.

Calhoun and Warren (2007) indicate that although there are some limitations with the system created by Astley and Clarren, the Canadian guidelines, created in part by Albert Chudley, merged both the criteria developed by the IOM and those presented by Astley and Clarren. The authors continue by emphasizing the importance of a multidisciplinary team to conduct the assessments and determine diagnoses (Calhoun & Warren, 2007; Cook et al., 2016). The next stage of instrument development saw the Revised IOM Diagnostic Classification System followed similar methods to that of the Canadian guidelines; a multidisciplinary team (including; a social worker, psychologist, occupational therapist, speech-language pathologist, and development pediatrician) (Rasmussen et al., 2010), objective methods of assessment, and ensuring that diagnoses were determined on the FASD continuum. The assessment criteria retained “the 4 commonly accepted, key diagnostic criteria features of FAS, i.e., growth deficiency, characteristic FAS facial phenotype, central nervous system damage/dysfunction, and alcohol exposure in utero” while focussing more on neurobehavioural characteristics than facial or growth deficiencies (Hoyme et al., 2005, p.41). The instrument was then “field tested in a large multi-racial international cohort of children prenatally exposed to alcohol and have been found to accurately define the range of FASD” (Calhoun & Warren, 2007, p.170). Although

there are more definitive diagnostics for the assessment of those with the full spectrum disorder, there is still limited validity in the tools that assess the variants of the disorder (Calhoun & Warren, 2007).

At this point it needs to be acknowledged that there are debates over the exact extent to which researchers and physicians understood the impact of alcohol on developing fetuses. Warren and Hewitt (2009) state that there is much debate between FASD historians about the level to which the disorder was truly comprehended at the time; complicating the matter further are the societal views of alcohol at the various times of research and analysis. Societal paradigms such as the temperance movement and religious views on alcohol consumption as well as, the lack of understanding of what were inherited traits versus those caused by exposure to alcohol during conception and in utero created politically charged situations where the ability to discover unbiased information may potentially be unavailable.

### **Current Diagnosis of FASD**

The current state of Fetal Alcohol Spectrum Disorder (FASD) is best understood from the intersection of societal views, medical understanding and the physical and cognitive abnormalities exhibited by those with the disorder. At present what we know about FASD is an accumulation of the knowledge from the past, and the research being conducted in the present. The umbrella term FASD encompasses the spectrum of disorders which are described as fetal alcohol syndrome (FAS), alcohol related neurological disorder (ARND), prenatal alcohol exposure (PAE), alcohol- related birth defects (ARBD) (Warren & Hewitt, 2009) and Partial FAS (pFAS) (Carpenter, 2011). With an addition of the term neurobehavioral disorder with prenatal alcohol exposure (ND-PAE), focusing on the neurological impairments with or without the presence of physical characteristics normally associated with FASD (Hoyme, et al., 2016).

These disorders are now known to be a result of pre-birth maternal alcohol consumption, resulting in a range of primary and secondary disabilities and often producing cognitive delays. Thus a valid diagnosis may be difficult to obtain as maternal pre-birth alcohol consumption is often thought of as a taboo topic, which can produce feelings of shame (Olson, Oti, Gelo & Beck, 2009) and ultimately not one to which mothers may readily admit (Rasmussen et al., 2010). This becomes especially true as knowledge of the effects of a diagnosis become evident, as more and more it is understood that the disorder includes a range of impairments such as; mental retardation (Rasmussen et al., 2010); limitations to the growth and structure of the body and brain (Hoyme, et al., 2005); complications to the central nervous system; and behavioural difficulties and characteristic facial deformities (Burd et al., 2003). In addition, many children with FASD are in foster care from birth, with little knowledge of what alcohol exposure they may have had, further complicating the ability for an accurate diagnosis (Burd, Cotsonas-Hassler, Martsof & Kerbeshian, 2003). Roozen et al. (2016) agree that when knowledge of maternal drinking can be found out it should be, however it is still debatable on whether or not it should be a requirement for a diagnosis. If it is not obtainable, other relevant evidence should be used to make the determination.

However, there may be a case for not accepting FASD as the solitary diagnosis for all children's syndromes as Hoyme et al. (2005) indicate that "many genetic and malformation syndromes have some of the clinical characteristics of FAS and children with other genetic and dysmorphic syndromes are born as frequently to women who abuse alcohol as they are to other women in the general population" (p.41). With this knowledge comes the assertion that not all children born with the characteristics of the disorder fall into the spectrum and may indeed have something completely unrelated to FASD, such as Williams syndrome or Cornelia de Lange

Syndrome<sup>3</sup> (Davis, Desrocher & Moore, 2011). Hoyme et al. (2005) points out that when misdiagnoses are made it can have profound effects, such as labelling the child and stigmatizing the mother. Ultimately, even beyond the emotional effects that a misdiagnosis may have there could be further social implications such as inaccurate treatments, inappropriate referrals to programs and lack of services provided by social agencies that provide disability services for genetics conditions such as Williams syndrome. Hoyme et al. (2005) contend that often when physicians suspect that children may have FASD, all other possible explanations are discarded, they state that, “a diagnosis in the FASD continuum should not automatically be assigned to a child with disabilities, merely because his or her mother drank alcohol during the pregnancy” (p.45). Other studies indicate though that misdiagnosis can go both ways, as children with the disorder may be classified as having autism (ASD), Asperger’s (AS), obsessive compulsive disorder (OCD) or attention deficit hyperactivity disorder (ADHD). However when they are assessed to have one of those disorders it is often on account of the behavioural characteristics which they display and not because of any knowledge of alcohol related damage (Carpenter, 2011). The most likely misdiagnosis that children with FASD obtain is that of attention deficit hyperactivity disorder (ADHD) (Coons, 2013).

Hoyme et al. (2005) indicates that based on the criteria set out by IOM, in order to be diagnosed with FASD, children must have abnormal characteristics in all of the following areas; growth, dysmorphic facial features and brain growth and/or structure. For a diagnosis of partial FASD they must have dysmorphic facial features in addition to deviations in one of the other two categories. In terms of obtaining a diagnosis of either one of the alcohol-related effects

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<sup>3</sup> Cornelia de Lange syndrome is a disorder that varies from mild to severe affecting many developmental areas pre and post birth. Characteristics include; shorten height, cognitive delays, abnormal extremities and atypical facial features.

categories (ARBD or ARND), a documentation of prior maternal drinking is required as children under those categories of the disorder may not exhibit prominent symptoms. Hoyme et al. (2005) explains that children with ARBD have either major or minor variances in specific structures but have normal facial features and development; while ARND indicates children with normal development but who have abnormalities in the areas of behaviour and/or cognition. Davis et al. (2011) argues that “[f]acial dysmorphology is often considered the cornerstone of FAS; however as stated earlier, there are a number of alternative syndromes that share similar facial features (e.g., Cornelia de Lange Syndrome). For this reason, facial features cannot be used on their own to diagnose FAS (p. 146)”. Conversely, some children who fall into the FASD continuum do not display any abnormal facial features. In fact only a small percentage of those with FASD may have those features and thus in these instances as well, facial features cannot be used as a definite indicator of the disorder (Davis et al., 2011). Further evidence of this has recently come to light with the acknowledgment that there needs to be additional or different criteria for diagnosing Caucasian children as their facial dysmorphia may differ from that of other ethnic groups (Hoyme et al., 2016).

The extent of alcohol exposure and the trimester in which it happened may have influence on the types of facial and growth abnormalities that children with FASD display, which could include both features required for a diagnosis (discriminating), including; thin upper lip, an indistinct philtrum<sup>4</sup>, microcephaly<sup>5</sup>, short palpebral fissures<sup>6</sup>, and associated features, including; minor ear anomalies, a low nasal bridge, epicanthal folds<sup>7</sup>, and micrognathia<sup>8</sup> (Riley

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<sup>4</sup> Philtrum is the tear drop shape of the skin below the nose and upper lip, which can be absent in people with FASD.

<sup>5</sup> Microcephaly is an unusual smallness in head circumference often associated to cognitive impairments.

<sup>6</sup> Palpebral fissure length is the measurement between the inside and outside points of the eye.

<sup>7</sup> Epicanthal folds are the pink fold of skin located in the inner most point of the eye.

& McGee, 2005), a small head (Astley & Clarren, 2000), abnormal or no genital organs, a malformed heart, and can be smaller than their peers (Carpenter, 2011). Children can also face neurological and intellectual impairments, such as; memory problems, language impediments, learning deficits, coordination and motor skills, language abilities, and executive functioning (Davis et al., 2011). Additionally, behavioural and social deficits are also common place in children with FASD, cumulating in a wide variety of deviances, including; lying, cheating, stealing, delinquent behaviour, lack of inhibition (Davis et al., 2011) and difficulties understanding social cues (Hellemans, Sliwowska, Verma & Weinberg, 2010).

Chudley et al. (2005) report on the Canadian Guidelines of FASD diagnosis, which outline the nine domains (structure of the brain, communication skills, scholastic ability, executive functioning, attention span, memory, motor/sensory skills, and ability to adapt) that should be examined to determine the presence of the disorder. The authors further note that;

A domain is considered “impaired” when on a standardized measure: Scores of 2 standard deviations or more below the mean, or there is a discrepancy of at least 1 standard deviation between subdomains...Evidence of impairment in 3 domains is necessary for a diagnosis, but a comprehensive assessment requires that each domain be assessed to identify strengths and weaknesses (Chudley, et al., 2005, s9).

These guidelines and the assessment which result create some of the most crucial underpinnings to how clinicians, social workers and educators determine what interventions are necessary, and how they are best adapted to meet the needs of the individual child (Chatterley-Gonzalez, 2010). As with all works in progress there were some limitations to the diagnostic guidelines set out in 2005, in that the areas of “...levels of deficit and affected functional domains were not clearly articulated (Hoyme et al., 2016). With the recent changes to the guidelines initially set out by Hoyme et al. (2005), the focus of the updated criteria for FASD

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<sup>8</sup> Micrognathia is the unusual small size of the upper and/or lower jaw.

diagnosis looks to increase the sensitivity of the instrumentation as well as having increased inclusion for all children no matter where on the spectrum of FASD or its umbrella disorders they fall into (Hoyme et al., 2016).

### **Factors that Influence FASD Diagnosis**

A diagnosis of FASD is not as simple as having the sole influence of maternal drinking on an unborn fetus. There are a variety of other factors which intersect and may play a role in a child being susceptible to FASD. Burd et al. (2003) explain that both internal and external factors play a role in the onset of the disorder; pre-natal and post-natal environment, genetics, nutrition, socio-economic status, race, older maternal age at conception, term of pregnancy (Kalberg & Buckley, 2007), single mother household, parental drug use, familial custodial changes, and mothers' educational status (Davis et al., 2011), can interact to predispose a child to be diagnosed within the FASD continuum.

It appears that family history may also have a strong influence on risks of having children with the disorder. Burd et al. (2003) states that sixty-one percent of women who have issues with alcohol consumption were born to a family where either one or both of their parents were alcoholics. Current research indicates that less than 5% of women who have severe problems with alcohol consumption that get pregnant, will have a child that is affected more severely with the disorder (Davis et al., 2011). However when a child is born with the disorder there is up to a 75% chance that any further siblings would be at an elevated risk of being born with a similar condition if their mother continues to consume alcohol (Burd et al., 2003). Millar et al. (2017) agrees that there are a number of factors that influence FASD, adding “[t]he effects of FASD vary in range and severity for each individual, likely depending on individual biology, genetic and epigenetic factors and environmental influences (p.4)”. Although all those factors can play a

role in the development of FASD, Chudley et al. (2005) indicates that the only surety on a child being diagnosed on the spectrum is "...high blood-alcohol concentration: the timing of exposure during fetal development, the pattern of consumption, i.e., binge drinking (4 or more drinks per occasion) and the frequency of use" (p. S2). To date there have been no large studies on risk factors. This lends to difficulty in determining the actual level of risk of FASD that a child faces because the factors that are considered to be a determinant of FASD may not be comparable across different populations (Chudley et al., 2005).

### **Development of FASD**

Current medical research does not provide accurate figures for the amount of alcohol which a pregnant woman can consume before causing damage to her unborn child (Carpenter, 2011). The Center for Disease Control (CDC) in the United States of America indicates that "...no amount of alcohol consumption can be considered safe during pregnancy" (CDC, 2005 p.1) while Carpenter (2011) states that "[t]he amount of alcohol necessary for foetal damage is unclear, and it remains debatable whether there is a threshold below which alcohol does not harm the foetus" (p.37). Based on those and similar results, the U.S. Surgeon General decreed that expectant mothers or women who may become pregnant should not consume any alcohol (Kotrla & Martin, 2009)<sup>9</sup>. Kotrla and Martin (2009) do point out that heavy drinking or binge drinking does pose a greater risk for children being affected by alcohol in utero. Complicating this matter further is that alcohol affects each individual woman differently depending on; how she metabolizes alcohol (Riley & McGee, 2005); genetics (Kalberg & Buckley, 2007); term of pregnancy; fetus development; and genetic and environmental factors (Burd et al., 2003), can all be contributing factors in the development of FASD.

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<sup>9</sup> The United States Surgeon General made that statement in 2005 through an "Advisory on Alcohol Use in Pregnancy" Centers for Disease Control and Prevention.



There is further indication that alcohol consumption at different times in the pregnancy can have varying effects on the fetus. Although many women may not even know they are with child in the first trimester of their pregnancy, the effects that drinking has on brain development remain the same (Koltra & Martin, 2009). Evidence suggests that damage in the first three months of pregnancy is in the areas of abnormal brain development and facial dysmorphology. While in the last three months of pregnancy, damage can occur to the prefrontal cortex, the hippocampus or the cerebellum (Davis et al., 2011).

### **Brain Domains**

Davis et al. (2011) reports that the developments in imaging technology have increased the ability of researchers to study “brain anomalies of individuals at different points of the FASD spectrum” to provide better understanding of how the condition affects these areas, which can eventually lead to more comprehensive interventions and treatments (p.147).

Children with FASD often face multiple brain deficits including; hippocampus<sup>10</sup> damage resulting in reduced abilities in spatial and verbal memory (Mattson, Schoendeld & Riley, 2016); underdeveloped basal ganglia<sup>11</sup> resulting in lack of motor coordination (Clark et al., 2000); reductions in processing speed and ability to carry out tasks; reductions to the orbitofrontal lobe<sup>12</sup> which could result in decreased abilities in specific areas of executive functioning (Davis et al., 2011). There are also comparable cerebral blood flow patterns between children with FASD and ADHD which may be the reason for similar deficits in behaviour (Riikonen et al., 1999); and

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<sup>10</sup> The hippocampus is the bottom fluid filled cavity in the brain, formed of gray and white matter whose purpose is to store, form and process memories.

<sup>11</sup> The basal ganglion is the four gray matter masses located in each hemisphere of the brain.

<sup>12</sup> The orbitofrontal cortex is the moral center of the brain that drives a person to make decisions, and acts as a moral predictor on what action to take. It is influenced by present and past results and whether those results elicited either pleasant or unpleasant emotions.

finally, MRI results indicate that “children with FASD showed a decrease in inferior frontal cortex functional activity with increasing task difficulty, while control children and adults showed the opposite pattern” (Malisza et al., 2005). Janzen, Nanson and Block (1994) further indicate that “the more severe the growth retardation, the more severe the impact on cognitive abilities, yet it is unknown whether growth can be used as a predictor of intellectual potential in younger age groups” (p.274).

Hellemans, Silwowska, Verma and Weinberg (2010) examined the correlation between the hypothalamic pituitary adrenal axis (HPA) and how it impacts depression and anxiety within individuals that have been diagnosed with FASD. HPA is thought to have a crucial role in maintaining the balance in hormone levels in the human body, which has a significant impact on depressive episodes in individuals with FASD. Additionally, decreased levels of monoamine<sup>13</sup> activity may have an impact on how impulsive and individual, as well as their suicidal behaviours (Hellemans, et al., 2010). Another effect examined was cortisol reactivity<sup>14</sup>, with findings indicating that it produced increased heart rates and negative affect. These results differed between genders as females had “greater changes in heart rate and negative affect than boys and boys showing greater changes in cortisol than girls” (Hellemans et al., 2010, p.797). When compared to children of normal development and growth, those with FASD exhibit significantly lower IQ levels (Kooistra et al., 2009).

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<sup>13</sup> Monoamines are a neurotransmitter with only one amine, release by neurons in the nervous system and the brain. Monoamines are believed the play a central part in cognition, emotions and arousal.

<sup>14</sup> Cortisol reactivity occurs when the adrenal gland releases a steroidal hormone, during periods of stress, that regulates blood pressure, and the metabolism of carbohydrates.

## Secondary Disabilities

When discussing the impairments of FASD there needs to be a differentiation between whether the disability is primary or secondary in nature. Streissguth (1997) defines these disabilities as follows;

...primary disabilities are defined as functional deficits that reflect the CNS dysfunctions inherent in the FAS or FAE diagnosis. Secondary disabilities are those that arise after birth and presumably could be ameliorated through better understanding and appropriate interventions (p.27)

In other words, primary disabilities are those that are inherent in the disorder; those incapacities or deficits which the disorder creates. On the other side of the equation are secondary disabilities, co-occurring disorders that are either complements (e.g.; ADHD) to FASD or may be brought on by behavioural (e.g; drug and alcohol dependency) or cognitive delays (e.g; learning disabilities) (Chatterley-Gonzalez, 2010). Hanlon-Dearman et al. (2015) mentions that co-morbid mental health conditions affect over 90% of people who have the disorder, with ADHD being the most common. Davis, Desrocher and Moore (2011) indicate that secondary disabilities can develop over the life span and will affect not only the individual with FASD, but also their families, and ultimately all of society will suffer from the costs associated with secondary disabilities.

Statistics on secondary disabilities, compiled by Streissguth (1997), from a long term study examining children with FASD, indicated that they had much higher rates than average in the number of areas. Almost all (95%) had issues with mental health, more than half had problems in school (60%) or with the law (60%) respectively, approximately half (55%) were in incarcerated in a number of different places (addiction treatment programs, prisons or mental health facilities), 52% behaved in inappropriate sexual manners, 70% had issues with employment, the majority (82%) could not live independently, and more females (70%) than

males (50%) had problems with drugs or alcohol. In two studies, one in Canada and another in the United States, researchers found that youth with FASD were significantly more likely to be incarcerated than their non-affected peers (Department of Health and Human Services, 2007; Popova, Lange, Bekmuradov, Mihic & Rehm, 2011). Although those statistics are from the US, a study conducted in Canada found similar results as, Popova et al. (2011) discovered that youth with FASD were incarcerated at a rate of 19 times higher than that of their peers, while over half of those with FASD have had some contact with the law and that over a third has been incarcerated at some point in their lives.

Mukherjee, Commers, Hollins and Curfs (2013) also point out these children often do not complete high school, often as a result of society's inability to understand and accommodate the needs of this group. Looking at a Manitoba context, Gough and Fuchs (2006) outline some statistics on the disabilities that children receiving service from CFS in the province display. Although these results are not specific to children with FASD as those from Streissguth (1997), they still provide some valuable insight into the population of children in care in Manitoba. One-third (33%) of children presented with a disability, with over half of those children displaying more than one disability. The most frequent disabilities were; intellectual (75%), mental health disorders (56%); medical (22%); physical disabilities (6%); learning disabilities (6%) and sensory disabilities (5%). For those children with more than one disability, 27.5% had both an intellectual disability and a mental health concern while almost all of them (96%) had a mental health concern, an intellectual disability or both of them and that 84% of children who presented with a mental health concern were placed on a prescribed medication (Gough & Fuchs, 2006).

Burd et al. (2003) indicates that "one of the most important components in management of all patients with FAS is the prevention of secondary disabilities" (p.684). Children with the

disorder are more vulnerable to suicidal thoughts and actions, potentially brought on by the comorbid disorder of mental health concerns, and often misunderstood (O'Malley & Storoz, 2003).

Both biological and environmental factors have an impact on the mental health of individuals with FASD, with the greatest influences occurring when those factors interact with one another. Streissguth and O'Malley (2000) note that environmental factors such as; being removed from their biological home by child welfare agencies, lack of placement stability, instances of neglect or abuse, alcoholism in the parental family, maternal mood, death of the primary parental unit, and ongoing involvement with the child welfare system (Hellemans et al., 2010) can contribute and amplify the effects that a primary disability already has on an individual.

Mental illness rates are generally higher in vulnerable populations, such as persons with FASD; with some outcomes having higher associations with a particular gender. Thus males are more likely to suffer with addictions issues, while females have a higher tendency for depression and it developing into a comorbid condition to FASD. Overall, anxiety and depression are known to be the highest reported mental health concerns that are associated to individuals with FASD. External stressors can be argued to be a contributing factor to the onset of depressive episodes, and will often have more of an impact on individuals with FASD than those without the disorder (Hellemans et al., 2010). The authors also advise that since mental health issues such as depression and anxiety may also “have a neurobiological basis and thus, at least in some instances, could be primary rather than secondary disabilities”, and that the “increased risk for depression is not related to mental retardation, as the link between prenatal alcohol and depression” also happens with those of normal cognitive abilities (Hellemans et al., 2010, p.793).

Although mental illness can occur in both individuals with FASD as well as those without, it is often a co-morbid condition to FASD, and should be carefully assessed to ensure that a proper treatment plan account for those additional factors. However, Hanlon-Dearman et al. (2015) states that “there is no evidence-based literature supporting the unique management of mental health disorders in FASD” and further indicates that “anecdotal evidence suggests that the responses of medication are not predictably robust and may result in the prescribing of multiple medications” (p.36).

O’Malley and Storoz (2003) state that “[a]ggression or rage attacks were the second most common problems in children with FASD” (p.485), and this finding was even more significant for those who had witnessed violence in their home or “have suffered reactive attachment disorder because of removal from their birth parents” (p.485). Contributing factors to these attacks may be due to touch sensitivity, or even the overwhelming paranoia brought on by the effects from long-term use of psychostimulants. Researchers theorize that the use of atypical antipsychotics, such as Risperidone<sup>15</sup>, may provide some control of those behaviours (O’Malley & Storoz, 2003). Preliminary research shows that parents of children with the combined disorders of FASD and ADHD note that it is dependent on when their children were diagnosed as to what behaviours they present. Connor et al. (2003) observed that depending on the age of onset of ADHD it may impact the comorbid internalizing and externalizing conditions that the individual will develop. The authors further point out that those who are diagnosed early in their lives present more aggressive behaviours, while being diagnosed later leads to more a combination of more anxious and depressive characteristics. Doig, McLennan and Gibbard (2008) indicate that deficiencies in attention span produce more difficulties than hyperactivity for children with FASD. O’Malley & Storoz (2003) state that “children with FASD are commonly

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<sup>15</sup> Risperidone is an antipsychotic drug.

not mentally retarded but [do] present complex learning disabilities” but that they do often have severe co-occurring disorders such as “[c]omorbidity psychiatric conditions [which] include anxiety, mood, conduct or explosive disorder” (p.477).

Rasmussen, Horne and Witol (2006) tested 50 Canadian children with FASD to determine if there were significant differences based on various demographic characteristics. All those tested showed brain dysfunctions but not facial characteristics, as FASD is often an invisible disability. All of the children in this study diagnosed with FASD did, however, show impairments on intelligence, memory, inattention and executive functioning.

### **FASD and ADHD**

As there are no definitive medical tests or no particular markers (i.e. neurological, cognitive or metabolic) which can determine the presence of ADHD in children; this leads to large variation in the prevalence rates, which can range from anywhere between 0.5% and 26%, (Timimi & Taylor, 2004). There is no accurate measuring tool to properly assess the condition. There are a number of different scales which are used to assess the presence of FASD, including Conners’ rating scale, or the ADHD Rating Scale-IV<sup>16</sup>, but no definitive tool.

O’Malley and Storoz (2003) state that when FASD is combined with ADHD it is much harder to treat because of the compounded effects of the additional disorder. This can be problematic as Burd and Christensen (2009) indicate that anywhere between 15% and 73% of individuals who have FASD have the co-occurring disorder of ADHD. This matter is compounded by the prevalence of mental disorders in this population, as “56% were diagnosed with, or suspected to have, a mental health related disorder” (Fuchs et al., 2009, p.234).

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<sup>16</sup> The Conners’ scale is a check list used by parents and teachers to reliably assess ADHD characteristics in their children or students.

Kooistra et al. (2009) examined the differences which FASD and ADHD had on children and found that children with some forms of ADHD had problems with being under stimulated while those with FASD had problems being overstimulated. The authors further stated that “[i]nterestingly, children with ADHD were found to be impulsive, unlike the children with FAS[D]” (Kooistra et al., 2009, p.205). Coles et al. (1997) had similar findings with results indicating that ADHD often left children with the inability to focus or sustain their attention, while children with FASD could not properly encode information or shift what they had learned from one instance to another. There are some indications that the possibility that these behaviours could decrease as individuals age as O’Malley and Storoz (2003) found that animals that were hyperactive, due to being exposure to alcohol before birth, often experienced a reduction in that behaviour as they aged.

### **Parenting Children with FASD**

Parents of children with FASD must recognize that their role as caregivers is unlikely to diminish even when their children become a legal adult. When families understand how FASD affects their child, they are more able to adapt to better deal with the disorder (Coons, 2013). Sanders and Buck (2010) use the term ‘lifelong parent’ to denote that children with FASD will need and depend on their mother and father for support throughout their adult life. Olson, Oti, Gelo and Beck (2009) add to that idea, saying that FASD is a disorder which will last throughout the lifespan. Sulimani-Aidan (2016) indicates that children with FASD continue to need support even after they are aging out of care. However, this can be problematic as there is often no support from the child welfare system for them.

Caregivers have the most impact on the outcome of how a child with FASD will turn out. Jones (2003) furthers this idea with a discussion surrounding the need to use a life-span approach



to support children with FASD. She argues that this model of approach is necessary to ensure positive transitions throughout their lifespan, especially at key points; such as entering the school system, going through adolescence and aging out of care. Caregivers have the power to create change and improve the lives of those affected by FASD (Olson et al., 2009). Those families who are more proactive in managing stress and solving problems when they happen show more positive outcomes than those who are reactive (Olson et al., 2009). Multiple authors state that there needs to be greater understanding of FASD within child welfare systems, and one way to develop this is to listen to parents of children with the disorder to glean from their experience that which experiential knowledge provides (Jones, 2003; Olson et al., 2009). This will benefit two fold; agencies will obtain the knowledge which they need to better serve that vulnerable population, while parents will feel that their expertise is valued and feel respected (Coons, 2013). Olson et al. (2009) contend that if there is integration between the service providers and parents, there may be less stress felt on the family units. Coons (2013) supports this by stating that families need the support of all those around them, especially from professional services.

Parental support is also crucial for children with FASD who remain with their birth families as problems within the home can offset their development. Mothers who drank heavily tended to interact less with their children, as well as being less responsive to their developmental needs. In response to their mothers' behaviours, children developed insecure attachments to their mothers along with internalized behavioural problems (O'Connor & Kasari, 2000). The negative effects were also seen on the mother as well, who exhibited depressive symptoms which could later be observed in their offspring (Olson et al., 2009).

Parents of children with FASD identified a number of strategies to cope with raising a child with FASD, they include: focus on positive aspects of parenthood not just the negative or

limiting ones (Kayfitz, Gragg, Orr, 2010) maintaining routine; picking battles wisely; maintaining a healthy level of spirituality (Coons, 2013); accepting their child as teacher to understand some of their behaviours; using appropriate interventions at major developmental stages; using interventions which are flexible and adapted to their child's specific needs understanding the limitations of the skills of the parents; emotional support provided by professionals; self-help parent support networks (Olson et al., 2009); having a network of both formal and informal supports; and developing a protective bond (Coons, 2013). Over time caregivers of children with FASD may experience significant levels of psychological distress (Olson et al., 2009). The authors then indicate that “[p]arents need respite to alleviate the stressor in parenting and to avoid burnout” (Olson et al., 2009, p.241). On the other hand, Jones (2003) states that when foster parent enjoys their foster child's personality chances of as long term placement is more likely and will impact the parent child relationship with positive outcomes.

Heller and Ganguly (2002) state that “increasingly these caregivers are grandparents who are caring for their grandchildren with disabilities” (p.21) and these blended families face different problems than those of a parent-child relationship. Family systems are often dynamic, having some potential stable elements (e.g.; structure), as well as ones that change on a continual basis (e.g.; functioning). Rearing multiple generations can cause additional changes in the family dynamics which may lead to further difficulties in children with the disorder (Coons, 2013). Children diagnosed with a disability (e.g. FASD) need a higher level of stability than the average child, Patterson and Gatwick (1998) indicates that families need to alter their functioning to be more adaptive to their child's needs. The author further exemplifies this by saying;

Rituals and routines provide some sense of stability as well as an identity for a family, and they can serve to provide a kind of anchoring point and a sense of balance when

stressful events happen that call for changes in the family system. (Patterson & Garwick, 1994b, p.6)

The U.S. Department of Health and Human Services (2007) adds to this by indicating a structured environment has been shown to be effective in helping individuals with FASD manage in their communities. The full picture of family life with children who have FASD remains unknown, however those who agree to participate in research studies often have profound resilience. Researchers may be getting a biased perspective as those families may be more functional than average. However, with that being said there is a substantial benefit to listening to the perspective of families that have gone through the struggles and have come out ahead of the game. They can serve as role models for all the families who follow (Patterson, 2002). Olson et al. (2009) point out that families will go through many turning points during the lifetime of their child with FASD (e.g., transitioning from elementary school to high school, moving from childhood to adulthood) and thus to provide the best support possible they need to obtain the guidance of those who have come before them. This is also true for youth aging out of the foster care system, as often they are left to fend for themselves, with studies indicating that there are greater chances that a youth with FASD may find themselves homeless, unemployment, unplanned pregnancy, addictions and involvement in the justice system (Chatterley-Gonzalez, 2010). One such area which may be difficult to understand for parents is the difference between the actual age versus the cognitive age of their child, through observing what others have done in a similar situation parents may be able to find acceptance in their own situation (Olson et al., 2009). The development of family protective bonds is one of the most important coping strategies (Coons, 2013).

## **The Cost to Society**

There is a wide discrepancy in exactly how many children are born with FASD in any given year, partly due in fact to the various methods by which FASD is counted and assessed (Burd et al., 2003). A study in Canada suggests the prevalence of FASD "...has been estimated at 1 in 100 people, which translates to more than 330,000 affected individuals in Canada (Cook et al., 2016, p.196)".

While studies from the United States indicate the low end of the range suggests a rate of one diagnosed birth per 10,000 live infants, while the high end of the range provides a rate of 19% or 190 per 1,000 live births (Burd et al., 2003). Burd et al. (2003) indicates that the most commonly accepted figures come from studies that estimate the rate to be approximately 1 to 1.5 children per 1000 completed births, which when calculated as a percentage produces a 0.0015% chance of an infant born with the disorder. The associated financial costs to society related to FASD can come in numerous forms including; lost productivity; higher costs for special education programs, increased medical expenses; and costs for social services provided (Davis, Descrocher & Moore, 2011). An analysis based on those expenses determined that the costs related to Canadian children and youth, aged one to twenty-one FASD totalled \$344, 208,000 per year (Stade et al, 2006). Popova, Lange, Burd and Rehm (2014) provide a picture of how many children are in care in Canada, broken down by province, as well as how many of those are suspected to have FASD, all to determine the costs associated with the care of children with FASD in Canada. The provinces with the highest number of children in care are; the Northwest Territories with 1 of every 32 children, Yukon Territory with 1 of every 41 children, and Manitoba came in third with 1 of every 41 children. When they added in the factor of FASD, they estimated that in Canada they are between 2,225 to 7,620 children in care that have the

disorder, with Ontario, Quebec and Alberta carrying the highest numbers. Popova et al. (2014) provides a range of estimated costs associated stating “the results of this study suggest that, in Canada, the annual cost for children in care with FASD is likely to range from \$57.9 to \$198.3 million (p.89)”.

There is a high degree of variance in the costs associated with FASD are likely due to the differences in costs which are being factored into the estimates and, as with prevalence rates, also due to the difference in diagnostics (Burd et al. 2003) . Burd et al. (2003) describes those estimates to include “...neonatal care, management of developmental delays and birth defects; years of special education; decades of developmental disabilities services; costs to the criminal justice system; alcohol and drug abuse treatment; mental health services; health care costs; and a lifetime of supported living costs” (p. 682). It is further estimated that the lifetime cost per case for an individual with FASD can reach US \$1.4 million (Burd et al., 2003). The staggering figures, increases in alcohol consumption and the knowledge that binge drinking has profoundly negative effects on the fetus and is reportedly on the rise with women of child bearing age (Davis et al., 2011), indicate that FASD spectrum disorders is a public health problem which should be considered a priority for preventative measures (Burd et al., 2003). Popova et al. (2014) also state that the actual costs to the system for keeping children with FASD in care should never be overlooked, but that there are many other additional direct and indirect costs to the system.

### **FASD and the School System**

There are a number of countries, including; the United States, Canada and Italy; that promote the use of inclusive education in the classroom. Inclusive education combines students with special needs, including those with FASD, into regular stream classrooms (Kalberg & Buckley, 2007). The Winnipeg School Division has in fact been a national leader in creating

innovate action plans for educating children with FASD (Millar, et al., 2017). The educational planning for each child with FASD should be specifically geared towards adapting to the brain deficiency and cognitive limitations, as well as, the strengths of the individual child.

Kalberg and Buckley (2007) state that;

Although children with fetal alcohol syndrome have the same diagnosis, the individual learning profile of each child is unique. Appropriate school interventions provide the necessary academic and functional supports so that the child can develop the necessary skills to become an independent adult (p.279).

This idea is still at the forefront as Brenna, Burles, Holslander and Bocking (2017) mirror this statement;

Given the variable nature of FASD all affected individuals will have unique experiences and abilities making it difficult to adopt a universal approach to education and support, however aspects of one case can be considered for possible application to another case (p.221).

The Winnipeg School Division understands the need for individually adapted programming, tailoring the environment and learning plan to suit the needs of the children's unique learning profiles.

Kalberg and Buckley (2007) indicate that it is abnormal or deviant behaviours that alert teachers and the school system that there may be something developmentally wrong with a child. Carpenter (2011) agrees that if there has not been a formal diagnosis of the disorder at in the pre-school years, the school then often becomes the first identifier. Popova, Lange, Burd, Nam and Rehm (2016) add that due to their behaviours, these children are often identified as difficult to manage in the classroom. They also advocate for teachers having more training to recognize what behaviours are potentially linked to FASD, to help identify those students for early interventions. Karlberg and Buckley (2007) suggest a list of factors which should be observed in

numerous settings, which include; skills, attention, independence, social interactions, functional language, strengths and interests and behaviour (p.282).

Part of educational planning involves the assessment of which interventions are best used in the classroom with children diagnosed with FASD. Carpenter (2011) conducted interviews with classroom teachers who were asked questions about identifying what challenges they faced and the adaptive methods that they used when teaching students with FASD. Teachers often remarked on the fleeting knowledge retention that children with FASD exhibit, pointing out that “[i]t was very obvious that retention and overlearning were not key features of the learning pattern of the child with FASD”, but continued their attempts to optimize the learning potential of the children. They listed ten of the most important learning challenges of children with FASD, while also identifying ten possible compensative techniques for educators. The learning challenges are; hyperactivity; short attention span; erratic mood swings; poor memory; lack of social skills; auditory/vocal processing; visual sequencing; sensory integration difficulties (particularly lack of co-ordination); poor retention of task instruction; and numeracy/mathematical difficulties (Carpenter, 2011, p.39).

Paley and O’Connor (2009) list strategies for educational intervention to combat those learning challenges, which include;

- (1) Implementing consistent and predictable routines, such as scheduling activities or tasks in the same order every day;
- (2) Providing numerous opportunities for behavioral rehearsal and practice, since children with FASDs require much more practice to acquire a skill than nonexposed children;
- (3) Making contingencies explicit (e.g., if you do X then Y will happen), which may help compensate for the difficulties these children have understanding cause and effect relationships and anticipating consequences of behaviour;
- (4) Breaking down verbal instructions into small steps to address receptive language problems and executive functioning impairments and aid in comprehension and performance of multistep tasks; and
- (5) Using visual cues and aids to accompany verbal instructions (p.260)

While Carpenter (2011) also lists many of the same strategies, he does add some of his own, such as; children should be in a quiet learning space, rooms that are sparse and without distractions, a supportive and affirming environment, frequent bouts of physical activity during the day, adequate time frames for task completion and varying teaching styles that encompass multiple learning styles.

Evidence suggests that children with FASD have problems in transferring what they have learnt in one situation or environment to effectively solve a similar situation in another environment (Kalberg & Buckley, 2007). McInerney (2001) states that this deficit needs to be accommodated within their learning plans, incorporating tasks with constant repetition, as well as, visual instructions to aid in the behavioural development. Overall Kalberg and Buckley (2007) stress that when working with children with FASD “it is helpful to think of the environment as an external nervous system of the child, a place where external (environmental) supports can be implemented to bolster the deficit areas of the child” (p.282). Further based on the idea of treating the environment as an external nervous system, Kalberg and Buckley (2007) urge that parents can also “change the environment to reduce problem triggers” (p.67).

Duquette et al. (2007) discusses the role of parents in the education of their children with the disorder, indicating that the more important predictor of a child’s educational success was the involvement of their parents in a number of different areas, including; advocating on their children’s behalf, monitoring the program that their children were part of, finding alternative resources or programs for their children, and providing both academic and emotional support. The authors further this evidence by providing an example with respect to transition programs, which attempt to ease students with FASD from their high school programs either into work or



into higher education. Results indicated that it was the parents who were the catalysts in getting their children in the programs, with little support being provided by the schools.

Teachers who have children with FASD in their classes should learn about FASD and effective teaching practices when dealing with the disorder. Dybdahl and Ryan (2010) interviewed 13 classroom teachers, who said that they either did not have training in the area of FASD, or if they did, it was not seen as effective. They felt that the training did not meet their needs to successfully prepare them to create alternative teaching methods for children with an FASD diagnosis. Popova et al. (2016) indicates that, "...there is an urgent need to develop and implement systematic training for teachers to better understand the needs of students with FASD and the best educational strategies when teaching them (p.174)". In a case study, one youth suggested that teachers take it upon themselves to learn more about FASD but most important message was not to judge (Brenna, Burles, Holsander & Bocking, 2017).

It is suggested that teachers should see parents of the children with FASD as authorities on both the disorder, and thus important sources of information on not only the disorder but the behaviours of their children as well. This may not be as easy as it sounds though as Sanders & Buck (2010) mention that even though they have a lot of knowledge about FASD, parents feel that their experience is undervalued by professionals. Dybdahl and Ryan (2010) indicate that in the interviews, the teachers who mentioned that when they did take the time to speak to the parents of children with FASD, saw it end in a positive result. However, they did indicate that they often did not have the time to do these kinds of follow ups.

Additionally, another possible barrier to this communication is that both foster parents and foster children may often face the stigma that comes from having the disorder (Jones, 2003).

Biological parents have the potential to face even further stigma than foster parents. Regardless of the potential stigma, parents should be included in the school lives of their children, assisting where they can whether it is with the delivery of programs or homework outside of school time (Duquette et al., 2007). Millar et al. (2017) believe that there are a few ways that this stigma can be mitigated, such as; if these children can be taught to understand that they learn differently than other children, “increasing acceptance among non-affected students and their families”, or even just letting families know that they are not alone (p.14).

Duquette, et al. (2007) examined the attributes of children with FASD who were successful in school and had a high potential to graduate from their program. Both parents and children from 16 households were studied, all of whom had adopted their children, and all diagnosed with FASD at a very young age. The most common identifier for success, when speaking to the parents, was the ability of the parents to advocate for their child. For the children the most prominent factor for success was having good friends, social connections (Duquette et al., 2007), as well as, “a high level of parental guidance” (Jones, 2003, p.211). The authors also pointed out that education about FASD on both the part of the parents and educators provided more opportunities for the children to be successful in school. This is especially important as barriers and difficulties can often lead students to drop out of high school completely (Duquette et al., 2007). Brenna et al. (2017) point out that youth with FASD often feel like they are different than other students, leading them to be insecure about their abilities in the classroom. The authors’ further point out that to combat this it is necessary to see the youth for their strengths instead of just their medical disorder. Teachers can also be instrumental, with the support of their parents in talking with medical professionals to create positive outcomes. Parents also identified that an educational program adapted to their child’s specific needs, along

with supportive educators aided in the success of their children at school. Parents of successful children also did their best in educating the classroom teachers about FASD and what it may potentially look like in the classroom (Duquette et al., 2007). Done correctly, innovate FASD programming may also have a positive effect on secondary disabilities, in addition to teaching social skills (Millar et al., 2017).

Duquette et al. (2007) found that the majority of adolescents, all of whom had FASD, indicated they had friends at school, a best friend, and felt that they did not have a problem making friends, however there were some respondents that did say they experienced difficulty in maintaining friendships. Parents of respondents further interjected that their children were often socially immature, and had difficulties differentiating between different levels of friendships.

Frankel et al. (2006) used quasi-experimental design<sup>17</sup> to examine the interaction of children with FASD in the classroom. They found that children diagnosed with FASD and ADHD have more difficulty obtaining and maintaining friendships. The authors found that best learning outcomes were seen from the children who were using a combination of the training and neuroleptic<sup>18</sup> medications, and that stimulant medication has extremely limited effect on the improvement of social skills. Millar et al. (2017) argue the necessity of helping children with FASD develop their skills and center on their strengths, in order to have more successful relationships and employment outcomes. Furthermore, when adapted cognitive interventions were given to children with FASD, they demonstrated a marked improvement in spelling, reading and writing skills (Davis et al., 2011; Popova et al., 2016). Unfortunately, there is a lack

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<sup>17</sup> A quasi-experimental design is one that mimics an experimental design but does not have random assignment of subject groups.

<sup>18</sup> Neuroleptic refers to the influence that an Antipsychotic drug has on a person, particularly on their behaviors. They can create a feeling of apathy, along with a reduction in initiative and a restricted range of emotions.

of information regarding both the cost of special education programming in Canada, as well as the percentage of children whom are using those services (Popova et al, 2016). They authors further indicate that by getting a understanding of the costs associated to the programming, schools and funding bodies can better plan for the special education needs of this population (Popova et al., 2016).

### **Social Work and FASD**

Children with FASD face much higher rates of contact with the child welfare system (CFS) than do their non-disordered peers (Astley, Stachowiak, Clarren, & Clausen, 2002). The demographic makeup of families in care tends to present a bleak picture of their upbringing, characterised by low socio-economic status, limited education and social disadvantage. Compounding these disadvantages is the marred history of Aboriginal people in Canada, which includes children being taken from their families in numerous instances (i.e. residential schools<sup>19</sup> and the Sixties Scoop<sup>20</sup>) resulting in generations of displaced people.

Fuchs et al. (2009) delivers the shocking statistics regarding the ethnic identity of kids in care outlining that “First Nations children make up 70.1% of the children in care and 68.7% of the children in care with disabilities (here, First Nations includes Treaty status, Non-status and Inuit)” (p.38). Children in isolated communities fair even worse, as the Aboriginal youth in remote Northern communities in Ontario have higher prevalence rates of not only FASD but also a variant of infectious diseases and social problems (MacMillian, MacMillian, Offord & Dingle,

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<sup>19</sup> Residential schools were religious lead education institutions, sanctioned by the government used to assimilate first nation’s children to adopt Euro-Canadian culture. It is estimated over 150,000 children were abducted from their homes and force to attend these institutions.

<sup>20</sup> The sixties scoop is a term that was given when Aboriginal children were removed from their homes and placed with non-native families during the 1960s to 1980s. Up to 20,000 First Nation children were affected from Canada, the US and even as far as Europe.

1996). Additionally, these groups are also overrepresented in the justice system with around 80% of the places in the Manitoba Youth Centre being occupied by Aboriginal youth. These numbers are substantial as, based on census data from 2011, the overall population of persons of Aboriginal descent is 16.7% in Manitoba (Statistics Canada, 2013) and only represents 4% of the population in Canada (Statistics Canada, 2015).

According to Besharov (1994) it is estimated that approximately 80% of children, who have FASD, and are under the age of five will grow up in CFS (Chatterly-Gonzalez, 2010), and have their stability and lives adversely affected by facing multiple placements and “transitioning from family environments to group homes to temporary emergency shelters to institutional care as their needs increase” (Jones, 2003, p.44). Additionally as a result of being placed in care, there is a higher likelihood that the children will suffer from some form of maltreatment (Paley & O’Connor, 2011); neglect and abuse (Burd & Christensen, 2009), problematic reunifications with unfit parents (Burd & Christensen, 2009), parents who also have FASD/ADHD (Burd & Christensen, 2009), all of which will have an impact on their mental health and development of secondary disabilities (Paley & O’Connor, 2011).

The majority of children with FASD often become permanent wards of the system, and will remain in the care of CFS until they reach the age of majority. At least half of those children have no contact with their families of origin, meaning that they also suffer a loss of their culture and identity (Fuchs et al., 2009). Douglas and Walsh (2013) call this loss of culture ‘the stolen generation’, indicating their disconnection from their culture, families and communities. Streissguth and Kanter (1997) indicate that having a child in care has further implications to their families as once a child with FASD is taken into the care of CFS, it is unlikely that any further children born to that family will be raised by their biological parents (Brown & Bednar, 2004).

Sadly, even though these statistics are known and there have been numerous advancements in FASD research, there are still limited studies on the topic within social work journals. Cook et al. (2016) state it best when they note that “despite 40 years of research, there are still gaps in knowledge and evidence related to the diagnosis of FASD” (p.196). Chatterley-Gonzalez (2010) explained that “systems working with young people with FASD are not meeting their needs and making accommodations for them as people with a disability. These systems are: child welfare, mental health, justice and education” (p.107). If the systems are not working to assist in the best ways they can, individuals with FASD may be at a loss for what to do. The role of social workers becomes especially important in this instance, attempting to create a bridge between the individual in need and the services they require.

When children come into contact with the child welfare system, it becomes the responsibility of social workers to arrange placements for children whose families cannot care for them. Social workers then need to ensure that all potential foster families are informed of the impairment and the lifelong implications of raising a child with the disorder;

Prospective foster or adoptive parents should reach their decision to become involved with a child on the basis of honest and informed consideration. It is unfair to expect families to take on the challenges and responsibilities of caring for a child affected by FAS without a clear idea of what this may involve (Cousins & Wells, 2006, p.381)

There is often a balancing act that needs to be dealt with; protecting the privacy of the children’s and biological parents health information, while still obtaining the knowledge that is necessary to help obtain a diagnosis to properly provide services for children in care (Paley & O’Connor, 2011). Making this process even more difficult is that biological mother will often times not be forthright with, or attempt to minimize the amount of alcohol that they drank while pregnant. Collecting as much information as possible and obtaining as full disclosure as possible

from the child's mother is paramount to providing appropriate supports and determining acceptable interventions (Paley & O'Connor, 2011).

Providing information and understanding for the foster parents is key to ensuring adequate placements, but the other side cannot be ignored either; the children involved in this process. They also deserve to have a good home and the opportunity for a fulfilling life, and that is precisely why Edelstein (1995) "recommends specialist pre-adoption counselling to guide adoptive applicants toward a successful evaluation of the risks and possibilities involved in adopting a child who has been exposed pre-natally to alcohol" (as cited in Cousins & Wells, 2006, p.381). Completely informing parents may not be easy, as previously stated that full disclosure may be difficult to obtain, but there are often other factors that could come into play as well, namely lack of diagnosis until a later age. Paley and O'Connor (2011) raise the alarming notion that many children with FASD in care do not receive a diagnosis until they are much older, resulting in missing years of possible treatments and interventions, and higher potential for suffering from secondary disabilities. This means that families need support throughout the lifetime of the child, not just at the beginning of the fostering or adoption process. Olson, Oti, Gelo and Beck (2009) indicate that one of the most important factors when planning out interventions for children with FASD, is to ensure that their families have adequate levels of support. While Streissguth et al. (1997) states that "infants affected by FASD required long term planning and extra supports" (as cited in Cousins & Wells, 2006, p.380). However, setting up those supports can prove difficult as Olson et al. (2009) point out that it is often problematic to find and then set up respite services for families. Above anything else, it is essential that families are supported in their care of the children as to attempt to avoid multiple foster placements as much as possible (Cousins & Wells, 2006). Overall, Streissguth (1997) notes that

these children need to be part of a loving and nurturing environment, which has stability and reliability in order to strive for the best possible outcome (Cousins & Wells, 2006).

### **Planning for Medication: A Social Workers Role**

In planning for medications the findings suggest that the decision for whether or not children are placed on medications is at the discretion of their caregiver and/or physicians (Leslie, et al., 2011). However, this is different for children in care as these decisions are made by multiple decision makers. The downfall of this setup is that they have many appointed decision makers, such as “biological parent, foster parent, child welfare worker, or an alternative decision-maker such as a guardian ad litem or judge (Cooper-Patrick et al., 1999 as cited in Leslie et al., 2011, p.340)”, but not necessarily one person that is held accountable to make them. Children who are in care are often left in limbo, and do not have an appointed person in place to follow up for the child which often results in an invisible hand that administers the medication.

At present children with FASD are commonly placed on a schedule of psychostimulants to manage their condition, rapid acting in the morning and then slow acting in the at some point mid-morning to early afternoon (O’Malley & Storoz, 2003). However, neither this course of medications or others such as Adderall<sup>®</sup> or Dexadrin<sup>®</sup> have been fully proven by any scientific evidence to aid with the management of FASD or ADHD as there have been no long term studies which have taken place (Clavenna & Bonati, 2014). Children who take these medications often feel like they are forced to do so, with over half of them stating that they would stop taking them if they could (Barnett et al., 2016).

Timimi and Taylor (2004) spoke out strongly against the dependence that is created on the medical system when the main intervention used for children with FASD or ADHD is to medicate them. Not only does it fundamentally remove the right of families to make their own



decisions, but it is an easy way out for social workers that do not require much skill or planning to enact. They further stated that:

By acting as agents of social control and stifling diversity in children, we are victimising millions of children and their families by putting children on highly addictive drugs that have no proven long-term benefits and have been shown in animal studies to have brain-disabling effects (Timimi & Taylor, 2004, p. 8).

Burd and Christensen (2009) indicate that there is a great need for much more clinical trials and research done with children with FASD to be able to have an effective baseline and comparisons to determine what effects medication and other interventions are having on them. Ozsarfati and Koren (2015) are clinical researchers who have conducted pharmaceutical trial, they indicate that families are often opposed to medications because of side effects and potential long-term damage. They do suggest that if the positive effects of medications outweigh the side effects, that the use of pharmacological interventions at least be considered. Millar et al. (2017) is not so forgiving of medications, saying that because there the brain domains affected for each individual vary so widely, that often medications and even cognitive behavioural therapies do not work.

Although there have not been much research done on the long term effects that these medications have on children, Hanlon-Dearman, Green, Andrew, LeBlanc and Cook (2015) do list some of the common side effects of stimulant medications. They indicate that difficulties sleeping, loss of appetite, lack of physical development and mood changes when the medications are wearing off are all common side effects. Additionally, they state that “consideration must be given if the adolescent or their family members are at risk of abuse, misuse or diverting the stimulant medication to a street drug when choosing to prescribe stimulants (p.e31)”. The authors further pursue the idea that caregivers and those responsible for the children should be learning more about alternative interventions to meet the individual needs of the child so we do

not become dependent on medication as a solution. They suggest being creative to meet their needs requires a multi-model plan of intervention and stress the need for more educational and psycho-social interventions to work alongside with medications (Burd & Christensen, 2009).

Finally, there is no information in the literature “on how these different caregivers and clinicians interact to determine treatment strategies for children in child welfare” (Leslie et al., 2011). The authors suggest that this area needs to be explored in future research and should also take into consideration the complex nature of authority surrounding who can provide consent to children being placed on medication for FASD management (Naylor et al., 2007 ).

### **Learning for the Future**

The overall message coming from the research is that not all cases of FASD are alike and that each child needs to be treated as unique person. Millar et al. (2017) adds to this by stating that “we also posit that effectively educating children affected by FASD is critical to get right if positive educational and social outcomes are to be realised” (p.4). Bennett (2009) states that there is a greater responsibility on the child welfare system of Manitoba to adequately plan and monitor children with FASD, as there are often special needs that come along with this population. Brenna et al. (2017) indicates that there is very little research exploring the lived experience of children and youth with FASD and experiences at school. It is necessary to do research in the area to gain better perspectives and understanding to create better interventions.

Interventions need to be multi-faceted, not relying solely on one type of treatment or another, but weaving in many approaches to work in concert with each other. Millar et al. (2017) suggests that it is best if a multi-sectoral plan is created between both the school and community in order to serve the needs of these children. Santostefano (1988) suggests an intervention strategy of Cognitive Control Therapy as being a promising approach to counter the effects of

FASD (Kalberg & Buckley, 2007). This strategy involves metacognition, relying on an individual's ability to be aware of how they process thoughts, in order to assess whether or not they are understanding new information correctly (Kalberg & Buckley, 2007).

Some interventions strategies go beyond the typical pharmaceutical or clinical approach, taking into account the importance of culture, community and peer support as avenues for learning and FASD management (Chatterley-Gonzalez, 2010). Gilligan (2000) advises that it is important to “listen very closely to the lived experience of children in foster care” (as cited in Chatterley-Gonzalez, 2010, p.22). Learning from those that came before that have had similar experiences and have had to work through similar struggles can bring a wealth of knowledge for children and families that are facing problems on a daily basis. In removing at least some of the stigma of having an FASD diagnosis can go a long way in bringing feelings of value and worth to both the children and their families. In addition to minimizing the stigma, we also need to focus on the strengths of the individual, rather than solely on their deficits. Brenna, Burles, Holslander and Bocking (2017) point out that if we, as a society, are going to move towards inclusion, we need to be focusing on strengths as it is imperative in addressing the of needs learners with an FASD diagnosis in the classroom. This idea is true however; this needs to go beyond just the classroom setting, and into society as a whole. We need to understand that everyone has different gifts and abilities and they contribute to society in their own way. This is best understood by those that have gone through this process with one youth saying “find your strengths, find your weaknesses and don't be ashamed of that because...once you know what you're good at and what you're not good at then...the world is yours...” (Brenna, Burles, Holsander & Bocking, 2017, p.223)

## Summary

Although the diagnosis of FASD may have only been around since the early 1970s, observations of abnormalities of children born to alcoholic mothers began long before that time. The effect of alcohol on unborn children is not a new problem, nor is it limited to one group or culture. As it affects all people globally but here in Manitoba, First Nations people are over-represented both with diagnoses of FASD, as well as, in the child welfare system. With medical and research advancements we know more about FASD than we ever have in the past, we have more understanding about how to recognize the disorder, and some promising interventions to provided solutions to those families dealing with a diagnosis. With these advancements, why then is it that so many First Nations children are placed on medications as the only source of treating the disorder, the effects and the efficacy of which are still as of yet undetermined? Further research is required not only in the area of what effects medications have on children with FASD, but also about how taking those medications affects their lives in both the short and long term.

## **CHAPTER TWO: Research Framework - Theoretical Foundations, Methodology and Data Collection**

The foundation of good research requires that it is guided by sound methodology and the appropriate theoretical perspectives. The research methods and data collection in this thesis were guided by several theoretical perspectives, including; ecological systems theory, strengths perspective, Aboriginal approach and anti-oppressive practice.

The fundamentals of each theory will be outlined, including their strengths and limitation, as well as how they connect to each other and to the topic of this research. Following the outline of these theories, a discussion of the research methodology beginning with data collection, the strengths and limitations of the study, through to the demographic profile of respondents will provide an overview of the research methods used.

### **Theoretical Perspectives**

Social work theories have evolved immensely over the years, shifting from a highly medical based pathology (Weick, 1983), to ones that take into account the resilience and adaptability of the human spirit (Saleebey, 1996). Theoretical models of the past often had those in need of social services as merely passive observers of their own destiny, held to the will of experts in their particular field (Weick, 1983). Weick (1983) outlined the underpinning of the process, rightly identifying the process by which the client interacted with their workers as the ‘giving over process’. The key defining feature of this ‘process’ was the client giving over their power to outside agents, in essence, “...bow[ing] before the expert knowledge of the professional” (Weick, 1983, p. 468). This article may have been written more than twenty years ago, however the description of those processes is still true to this day, often decisions are imposed on the client as opposed to the person or family being empowered to make the decisions for themselves. It is not the knowledge of experts themselves that is essentially in question; it is

however the notion of an individual's lived experience being so easily dismissed. Weick (1983) states;

The process of human judgment has been so radically overturned, and, as a consequence, knowledge that is naturally accessible to people because it is personal knowledge is no longer admitted or accepted by them. The result of what is their knowledge about themselves becomes partially or wholly hidden. (p.468)

With that in mind, the four theories and approaches that will guide this thesis base themselves in the holistic understanding of the human condition. Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1977) (now also called biological systems theory) (Paquette & Ryan, 2001) will provide the theoretical basis; with the strengths perspective (Saleebey, 1996); an Aboriginal approach (Verniest, 2006); and anti-oppressive practice (Gilligan, 2000) providing support. Healy (2005) indicates that one of the necessities that theory brings is that it can help frame the direction that the practice of social work takes, this is also true in the context of research. The theoretical models that are chosen will guide how the study is conducted and how the results are analyzed.

### **Ecological Systems Theory**

Ecological systems theory finds its beginning within various social and scientific fields, including biological ecology and social work's social survey movement, and brings to light the humanistic aspects of social and general systems theories (Siporin, 1980). Those general systems theories, popular in the 1960s within the psychiatric and social work fields, had strong ties to community mental health and treatment of individuals with mental illness (Siporin, 1980). Following the threads of those theories, Bronfenbrenner's ecological systems theory looks to understand an individual's situation based on the environment and systems, both micro and macro, with which they interact (Paquette & Ryan, 2001). The authors point to the underpinnings of the theory as "the interaction between factors in the child's maturing biology,

his [her] immediate family/community environment, and the societal landscape fuels and steers his [her] development” (Paquette & Ryan, 2001). The developmental basis for this theory came from concerns about the research initiatives, being conducted by developmental psychologists of the time, which Bronfenbrenner felt were too restrictive and limited in scope (Bronfenbrenner, 1977, Bronfenbrenner, 1994). His belief that learning only from studies that create experimental situations that are temporary, disconnected, and unnatural, inspired him to make the statement “it can be said that much of contemporary developmental psychology is the science of the strange behaviour of children in strange situations with strange adults for the briefest periods of time” (Bronfenbrenner, 1977, p.513).

This pioneering work by Bronfenbrenner resulted in numerous other studies that followed this model, and less than a decade later he could make the statement that, “studies of children and adults in real-life settings, with real-life implications, are now commonplace in the research literature on human development...” (Bronfenbrenner, 1994, p.38). He himself did not see his work as pioneering, simply that the thoughts that he had were becoming those of the society of the time. His humbleness on the matter have been disputed by those that have followed, who do indeed name him as the founder of these theories, which now bears his name (Paquette & Ryan, 2001). There are others that have also influenced the movement, as Pardeck (2015) lists a series of trailblazers in the field of ecological theory that have added to Bronfenbrenner’s foundations for the effective use of the theory in social work practice.

Pardeck (2015) indicates that work conducted by Carel B. Germain, Richard Grinnell, Roger Barker, and Ann Hartman produced significant advancements in the ecological perspective within the field of social work; their contributions to the perspective running parallel in time to developments by Bronfenbrenner. Ecological systems theory encompasses five

overall systems, as well as the individual; *a microsystem* (individuals or groups which have immediate impact on the development of the individual); *the mesosystem* (interactions between microsystems); *exosystem* (does not directly affect the individual but has impacts on one of the systems that surround them); *macrosystem* (the overall construction of systems within society) and the *chronosystem* (social beliefs and changes over time) (Bronfenbrenner, 1977).

By taking these systems into account this perspective allows social workers to work not only at the micro level of intervention, such as individual therapy, but also at the macro level of policy and resource planning. Pardeck (2015) indicates that “the present thinking of the ecological approach suggests that the primary premise explaining human problems is derived from the complex interplay of psychological, social, economic, political and physical forces (p.134)”. Siporin (1980) adds an interesting thought to take into account when looking at that interplay, “...an ecosystem consists of people, their life situations, and the well-functioning or dysfunctioning behaviour patterns that result from their interaction (p.510)”. Systems can interact with the individual in a number of different manners, which can impact individuals’ growth and development either in positive or detrimental ways (Paquette & Ryan, 2001). In her work, social worker Carel Germain speaks of the “goodness of fit” between the systems and the individual, and when there is a “misfit” between the two, it is critical that this conflict be corrected with an appropriate treatment (Pardeck, 2015). Siporin (1980) also places value on adaptive fit, as he emphasizes the “concepts of reciprocal complementarity, of resource exchange, and adaptive fit between sub-systems of person and situation, of client and milieu” (p.509). Rhodes and James (1978) suggest that there could be a cyclical relationship between the individual and their environment or the subsystems with which they interact. In other words, each system impacts an individual growth and development, which in turn affects how they



interact with that system, which ultimately adapts to reflect the new behaviours from the individual (as cited in Pardeck, 2015). Siporin (1980) adds another piece to understanding the interplay between systems as he indicates that ecological sciences take into account the mind, body and environment in all of these interactions.

Traditionally, interventions in social work regarding case management revolved around the idea that the deviant behaviours of an individual were related to their pathology. The ecological perspective views these behaviours differently, suggesting that “emotional disturbances... are disturbances resulting from a pattern of maladaptive transactions between the [individual] and the environment through which environmental activity shapes the person...” (Pardeck, 2015, p.137). The ecological approach takes the understanding that it is not always the person that is disturbed or deviant, it can be the result of a breakdown between the interactions of that individual and the larger social systems which surround them (Pardeck, 2015). This perspective views social functioning as changeable and dynamic, through the interactions which are happening between the individual and the environment (Pardeck, 2015). Thus effective interventions not only take into account the client they are working with but also attempt to work with the systems which surround them, which may be causing the conflict, to improve the social or functional situation of the individual (Pardeck, 2015). Siporin (1980) states that “an individual person can function well only if he [or she] has mature internal abilities and competencies, and has access to needed social resources in the way of positive, nurturing supports, facilities [services], opportunities, demands” (p.512). He continues that for individuals and communities to be productive, there needs to be adequate cultural, social and institutional supports which make this possible, and that conversely any inequity in those systems can foster dysfunction (Siporin, 1980). Hasenfeld also mentions that if the goals of the client and the goals

of society or of the organization are similar, it is likely that they will have a more trusting relationship (as cited in Siporin, 1980). Siporin (1980) states that interventions within the helping system needs to not only focus on helping individuals but to also change the systems that surround them, in order to produce lasting effects within the ecosystems involved. He further instills that we need to look to the greater picture, or macrosystems, in order to create changes at the individual level. Systems need to adapt and create programming and interventions that assist in creating supportive environments for children and their caregivers (Siporin, 1980).

Siporin (1980) outlines that one of the strengths of ecological systems theory is that it can be used as an assessment tool which;

...enables the identification of consistencies, strengths, and complementarities, as well as inconsistencies, discrepancies, and conflicts, in regard to particular systemic attributes and their relationships. The strengths and weaknesses involved in the internal structures and operating processes of subsystems also become evident (p.518).

This theory can also be used as an instrument for treatment planning, as it helps with the identification of fit between systems and individuals and how well the intervention fits

“...between the person and their situation, or between the client system and its milieu (p.518)”.

It also encourages social workers, or other helping professions, to take an multidisciplinary approach to interventions, using approaches from a number of different social systems to create the best treatment plan which fits not only the individual but also the environment which surround them (Siporin, 1980). Pardeck (2015) does disagree with Siporin (1980) stating that one of the limitations of ecological theory is that it does not “clearly define procedures for implementing the ecological approach in assessment and treatment of client problems” (p.133) and additionally that the theory is not well conceptualized. Additionally, another limitation it that it does not challenge the status quo, which essentially can leave oppressive systems in power in place (Siporin, 1980).

## **Strengths Perspective**

The strengths perspective finds its origins in the mental health system, working with individuals with extreme psychological problems. The perspective was developed as a countermeasure to the approaches being used at the time which focused solely on deficits, deviance and disorder (Healy, 2014). Saleebey (1996) states that “[the strengths perspective] requires composing a roster of resources existing within and around the individual, family, and community” (p.297), taking into account how pieces of their surrounding environment can have positive impacts on their developmental processes. This perspective looks to limit labelling the individual, to avoid using a one size fits all approach to programming and tries to focus on capabilities of the children rather than the problems in their lives , and to understand that “the problem is the problem – not the youth” (Hammond & Zimmerman, 2010, p.2). The authors further state that we should be asking what the individual does well and what we can do to support them, as opposed to what is wrong with them and how can we make them ‘normal’ (Hammond & Zimmerman, 2010). It empowers social workers as helpers to see the client with dignity, by placing value on the strengths of the individual with competency to self-determination (Healy, 2005). Recognizing that in order to facilitate change, interventions need to be solution focused instead of problem focused (Healy, 2014).

Hammond and Zimmerman (2010) list a series of factors that compose the foundation of the strengths perspective, including; don’t label look to the positives instead; facilitate change instead of trying to fix a problem; children need to know someone truly cares for them; guide them, do not be the expert; skill building is a life-long process; differences are to be celebrated; and the words we use can empower or destroy. Strengths perspective also opposes the dominant method of service delivery, “this is what we offer and the client needs to accommodate”, instead

trying to find ways to adapt the services or environment to fit what the individual needs (Hammond & Zimmerman, 2010).

Strengths perspective believes that individuals need support from many different individuals and systems which surrounds them (Hammond & Zimmerman, 2010). This is in line with ecological systems theory as they both recognize that the people and environment which surround the individual all play a role in how they behave. By using the strengths perspective to recognize an individual's strengths and then ecological systems theory to understand their surrounding environment, helpers can assist the individual to find their fit within their environment (Hammond & Zimmerman, 2010). Strengths perspective and Aboriginal approach both believe that everyone should be on the same footing, that everyone should be seen as equal. They also both attempt to acknowledge the individual's strengths instead of only looking at deficits.

There are limitations with this perspective; however, as it fails to consider the oppression that systems of power have on the individual. Because it focuses so heavily on the individual, it does not have the framework to bring about systemic change. It often does not consider the limitations of the individual, failing to recognize when they lack the capacity or ability to change (Healy, 2014). Strengths perspective also does not look at structures which can victimize persons with disabilities, whether they are physical, mental or emotional in nature. Furthermore, what constitutes strength is not clearly defined and thus could be very subject or judgemental (Healy, 2014).

The current approach to medicating children with FASD to manage behaviours is contrary to strengths perspectives as the focus is not on the strengths of the individual, instead centering on the management of their deficits. In order to facilitate development and create

change, the recognition of an individual's strengths need to factor into that approach (Hammond & Zimmerman, 2010).

### **Aboriginal Approach**

There is a long tradition of research in Aboriginal communities throughout history; to understand, adapt and thrive in the changing environment which surrounds them. The current research paradigm continues to follow a positivist tradition, believing that scientific inquiry provides the most reliable information on the human experiences. However, Castellano (2004) aptly notes that is in fact not feasible as "...human behavior is subject to many variables that interrupt linear cause-effect sequences" (p.104). This is greatly contrasted by the Aboriginal approach to research, which values insight and intuition as part of the process (Little Bear, 2000). Aboriginal science and research acknowledges that understanding not only includes humans, but also animals, the environment and the spiritual nature of all of those elements. Castellano (2004) purports that life encompasses all the interconnection of all of them. The dominant methodology, which can have elements of paternalistic control, often does not find value in intuitive thought or spiritual components within it scientific inquiry (Lavallée, 2009).

Kovach (2005) states that there has been so much research conducted on Aboriginal peoples, of which they have seen few benefits. Currently, research is seen as a negative entity among many Aboriginal communities, tainted by what they believe to be at best misguided and at worst harmful studies conducted by 'outsiders' (Castellano, 2004). Many communities feel that outside researchers come into communities and impose their methodologies with little consultation, while taking the results and disseminating findings without first ensuring that it is culturally sensitive and accurate (Schnarch, 2004). Potts and Brown (2005) indicate that "research can be a powerful tool for social change. It also can, and has been, just as powerful in

maintaining the status quo and supporting the evolution of societies that reward some people and inhibit others (p.260)”. Castellano (2004) points out that it is time for Aboriginal peoples to take charge of their research in order to have positive outcomes for communities and research that acts as “...knowledge creation for social benefits” (p.103). Schnarch (2004) reminds us that Aboriginal peoples have the right to be principal partners in the research that is being done within their communities and to determine “...what is real and what is valuable” (Castellano, 2004, p.102).

Some Aboriginal communities have found that participatory research has been a positive experience, believing that for research to be effective and encompassing that Aboriginal peoples need to be consulted along the way (Kovach, 2005). It should be noted however that participatory action research does pose some challenges of its own (Castellano, 2004) and that sometimes it does not contain any participatory or action elements within it (Potts & Brown, 2005). Aboriginal groups also want there to be less power differential between researchers and participants (Schnarch, 2004). Castellano (2004) furthers this idea by stating that the relationship between the researcher and the participants need to extend “...beyond the time and place of the exchange” and that “knowledge is not a commodity that can be purchased and exploited at will” (p.104). When researchers come in only for a short point in time, with no knowledge of the inner workings of the community, they do not have a full picture of reality of which they are studying (Castellano, 2004).

For Aboriginal peoples it is important to understand the individual in all aspects of their lives, an approach which the Medicine Wheel greatly represents. Verniest (2006) states that “...by considering these four states of being, the Medicine Wheel can examine a client’s location in relation to individual, family, community, and nation contexts” (p.1). The Medicine Wheel

represents balance; with all of its dimensions considered as equivalent to one another. The Medicine Wheel is represented by a circle which lends to “create a safe environment for people to share their views and experiences with one another” (Hart, 2002, p.61), leveling the playing field so each member has an equal voice (Hart, 2002). It takes into account a holistic approach, individuals/concepts/problems need to be understood and analyzed from many different directions or sides (Hart, 2002). The foundation of the Medicine Wheel allows an Aboriginal approach to take into account all of the pieces of a person in order to understand the whole, as well as making sure to hear and listen to the individual and their understanding of where they are in their life. Bronfenbrenner’s ecological systems theory recognizes some of the same components when analyzing an individual’s world, believing that it is the interaction of all of the systems, environments and people that surround the individual that have an impact on their behaviours (Pardeck, 2015). Both perspectives believe that it is multiple systems that impact the functioning of the individual and that there cannot be a mismatch or imbalance between those systems as it will create dysfunction on many levels.

Fundamentally there is a bit of a contradiction when using an Aboriginal approach in modern research. Traditionally, Aboriginal peoples have passed their stories down through oral tradition, not relying on written language (Kovach, 2005). This is especially true for Elders, which creates difficulties in that they have a vast and wealth of knowledge about their peoples, communities and traditions; which may go unrecorded (Sinclair, Hart, & Bruyere, 2009). This however does not fit with what research today requires, as it expects proof of knowledge and a written record upon which to base future research or findings. This is something that Aboriginal people have already begun to adapt to, realizing that written records are necessary to preserve culture and history. Castellano (2004) states that;

When Aboriginal peoples speak about maintaining and revitalizing their cultures, they are not proposing to go back to igloos and teepees and a hunter-gatherer lifestyle. They are talking about restoring order to daily living in conformity to ancient and enduring values that affirm life (p.100)

There needs to be balance and there needs to be choice. Research needs to follow cultural ideals that have been around for generations, yet needs to be adapted to fit modern times. Castellano (2004) states that research about Aboriginal peoples cannot be completed only by western methodologies. Sound research can only be accomplished if there is buy in from Aboriginal communities, but for this to happen Aboriginal peoples need be given the choice of how to pursue their own research, use their own methodologies. If research is imposed by systems of power that do not understand the culture and traditions, it ultimately creates imbalance and dysfunction.

### **Anti-Oppressive Practice**

Anti-oppressive practice rounds out the theories and perspectives being used in this paper. Brown (2012) discusses its origins as “discourse [that] has emerged alongside the larger social discourses of post-modernity within progressive social work, whereby the [merging], issues of diversity, difference, and oppression are now situated at the center in the commitment to social justice” (p.34).

Bishop (2002) states, whenever there is power over, oppression is unavoidable. Many theories, even those in social work, can bring with them strains of power embedded in their ideology. When this occurs, the interactions between worker and client or researcher and participant, cannot be void of oppression.

Utilizing an anti-oppressive framework is recognizing and being cognizant of power differentiation (Potts & Brown, 2005). As a researcher, and a social worker in the child welfare system, there is huge power differential. A safe place needs to be created, making sure to be



aware of the surroundings, tone of voice, and approach to asking the questions; in order to create a sense of balance during the interview process. This researcher will also be mindful of the words used in the demographic form, as they can create a power imbalance, as words do have power to build up or tear down (Saleebey, 1996).

It has been noted previously that this research is about listening to the voice of the children through their families. Gilligan (2000) states that in order to fully meet the needs of children in care we need to listen to what they are saying, in the case of this study through their caregivers. It is the hope that through this research the voices of the caregivers will be heard, and that their expertise can help to understand and implement changes in policy and services to better meet their needs, as well as, those that follow.

The ultimate goal is to place value in their lived experiences, and show them that they are a critical contributor to the research. The researcher's role needs to be seen, not as one of an expert, but rather that of a listener to their valuable expertise. It is also a means to empower, by allowing them to tell their stories in a safe and welcoming environment.

### **Overview of Theoretical Perspectives**

One of the main factors which is important for this thesis is the idea of a child's development being based on not only their biological condition but also their surrounding environment. Children may be born with a disorder such as FASD, which can cause social impairments (Davis et al., 2011), but coming from a stable and nurturing home environment can often help minimize the impacts on the underlying disorder (Coons, 2013). There are many factors which will impact a child's development, and those include; being in the child welfare system and the medications which are used to manage their behaviours. Through the use the aforementioned theories and perspectives this thesis will analyze the impact that both internal

(e.g., the child themselves, their foster home) and external (e.g., schools, child welfare agencies) have on the medication process and more importantly on the outcome.

The theoretical discourses which are used in social work practice are often borrowed from other disciplines, especially those in psychology and sociology (Healy, 2005). Different discourses or theories bring their own strengths and limitations with them, thus a number of theoretical perspectives will help fill in the gaps where the others are lacking. This meshing of theories does bring with it its own challenges however, as there may be some inconsistencies or contradictions between them. The approaches that a particular individual proscribes to are often based on a number of factors, such as their own social location or history, as well as, an understanding of the population with which they are working (Healy, 2005). In terms of this study, no single perspective can provide all of the guidance that is warranted, nor even does their combined effect achieve this goal.

## **Methodology**

Groenewald (2004) indicates that methodology can be difficult for new researchers to sift through as they not only have to understand the methods which they are using but also those that they did not select, in order to ensure that they were not the better choices for the job. The key is to understand how those differences, no matter how small they are, will impact the data collection and interpretation of any given study. This idea is especially true when choosing a qualitative design as many of the methods have slight variations between them. These debates encompass many aspects of the use of exploratory study including if the data interpretation should be more descriptive or interpretative in nature (Finlay, 2009). Yet what the precise parameters of this are, and exactly how this is accomplished in practice continue to be evaluated.

Brown (n.d.) indicates that the researcher takes on the role of an investigator; uses special methodology to recruit and select participants, obtain their stories, systematically analyze the data and take all the information that is collected and create a report. Lester (1999) speaks of how it is the description of the situation that is what the methodology is focused on describing, free from bias or preconceived theories, instead of trying to explain it. Although bias and prior theories cannot be truly removed from the research process, the aim in this type of methodology is to minimize as much of its influence and impact on data collected as possible. Brown (n.d.) continues by saying that stories and findings should be allowed to flow freely during the interview process, and should not be instigated or disrupted by the researcher. He further states that when writing up the findings from interviews, it is necessary to remain as close to raw data as possible; information should not be deleted, added, or changed, taking it away from the original idea or context set out by the participants. Additionally, it is also important to make use of 'bracketing', by making sure that any personal biases are well understood and do not impact or influence the findings. Lester (1999) advocates that researchers make the participants feel comfortable and ensure that they are empathetic to their stories. They should also maintain a "...minimum structure and maximum depth" practice for their interviews (p.2).

One of the strengths of exploratory study is that by listening to participants' stories, and gaining their insights and perspectives allows for normative and structural assumptions to be examined and challenged (Lester, 1999). He further indicated that "adding an interpretative dimension to research, enabling it to be used as a basis for practical theory, allows it to inform, support or challenge policy and action" (Lester, 1999, p.1)

## **Data Collection**

The data collection process for this study followed an approach, in accumulating information from both open ended qualitative (interviews and field notes) and the demographic form. Semi-structured qualitative interviews were conducted with 15 respondents; one interview consisted of two parts (from a couple) which were compiled into one interview. The field notes, observed during the interview process and written down shortly after the interview concluded, added flavour and depth to the words of the participants. Finally the quantitative data consisted of a demographic form. These forms collected the closed ended demographic and background information from the respondents, keeping it out of the interview to allow their story to more freely unfold.

## **Ethics Approval**

Permission was granted for the topic of this study by my research advisory team in September 2016 with the successful defence of my research proposal. Suggested changes were made to the proposal before submission to the *University of Manitoba Psychology/Sociology Research Ethics Board*, which approved my proposal in late December of 2016. Submitted in the approved proposal package was a submission form; a detailed outline of the study to be conducted; an informed consent form (Appendix F); the demographic form (Appendix G); an oath of confidentiality for research assistants (Appendix J); interview and telephone scripts (Appendix H & Appendix E); invitation letter to participate (Appendix C); request letter for advertisement posting (Appendix D) and recruitment letters (Appendix A) and posters (Appendix B).

## **Sample**

Because the population that was sampled is not visible (i.e., Manitoba foster parents of First Nations children in care), it required the use of both criterion and snowball sampling, which are both non-probability sampling techniques. Because of the specific inclusion and exclusion criteria, and the inaccessibility of the population, criterion sampling was the obvious choice. Snowball sampling was used as the secondary sampling technique, as interviewees had a greater potential in knowing other individuals that could fit the criteria of the study.

### **Inclusion/Exclusion Criteria**

Strict Inclusion/Exclusion criteria was followed for the recruitment of participants, which are outlined below;

#### **Inclusion:**

- The respondent must be a licensed foster parent in Manitoba
- Must be a current or former foster parent of at least one First Nations, which includes Inuit or Métis, child
- Children that they foster must be in the care of Child and Family Services (CFS) in Manitoba
- Foster parents may be of any ethnicity, as long as the foster child is of First Nations, including Inuit or Métis, descent
- Children in care must have been, are on medications, or were going to be placed on medications for the management of behaviours associated with known or suspected FASD or a related condition

#### **Exclusion:**

- Foster parents of children who were not in care of Manitoba CFS
- Foster parents that are not licensed to provide care in Manitoba

- Neither foster parents nor their foster children can be a part of the Berens River community, in and off reserve. This is because I am a Berens River City Supervisor, within Southeast Child and Family Services.

### **Participant Recruitment**

I began collecting my data in January 2017, by contacting a number of First Nations Child and Family Services agencies. I wrote a letter to the Executive Directors (Appendix A), and personally delivered them to the agencies. In keeping with my outlined recruitment strategy, I also visited various community resources and facilities to post my advertisement (Appendix D & Appendix B). Additionally, I contacted a few individuals that I knew met the inclusion criteria of my study to ask if they would be willing to be a participant (Appendix C). Many of those individuals agreed to participate in an interview. When recruiting to those individuals that I knew and they told other foster parents about the study, there was no coercion used to recruit them as I did not have any supervisory responsibility to the new research participants.

Whenever any potential respondents contacted me, or if I approached them, I would go through the inclusion/exclusion criteria and read the recruitment script with them (Appendix E), to ensure that they fit into the study and that they were fully informed (Appendix F) about what it entailed before we could continue.

One of the participants was so enthusiastic about being able to share her story that she asked for permission to take a copy of the recruitment poster (Appendix B) to their foster parent meeting to recruit further interviewees. There were many cancellations due to unforeseen emergencies, as the nature of the job of fostering can disrupt even the best laid plans. There were also a few individuals that called to participate in the study; however I could not complete interviews with them as they did not fit the inclusion criteria. I continued to check on the posters

(Appendix B) and letters (Appendix A) that I had sent out, again I had potential participants but many did not come to an interview.

With the interviews that I had acquired from my posters, word of mouth and the contacts from the foster parent meeting, I had just met my minimum goal of 12 participants. This was the minimum interviews as stated in my research proposal, however I wanted to reach out to hear as many stories and as wide a range of viewpoints as I could, and decided to visit a second round of agencies and service providers. One agency went as far as to put copies of the recruitment letter into all of their foster parents' monthly correspondences to aid in recruiting participants, which provided a few contacts.

Overall, I received a fair number of interviews from putting up the posters, but the majority of interviews came from snowball sampling techniques. Snowball sampling provided five out of the 14 interviews (35.7%), additionally I had four interviews from foster parents that I knew fit the inclusion/exclusion criteria which I approached (28.6%), and five from the recruitment posters (35.7%).

### **Interview Process**

When a potential participant was contacted, this researcher went through the inclusion/exclusion questions to verify that the contact could proceed to an interview. Once a fit was confirmed, an interview time was arranged at their convenience. The first interview took place on January 2<sup>nd</sup>, 2017, with the last interview taking place on May 1<sup>st</sup>, 2017.

### **Informed Consent and Obligation to Report**

Prior to the beginning of the interview process, the participants were provided with informed consent (Appendix F), informing them of their rights and responsibilities of the

researcher for the duration of the study. This information also included the exception to confidentiality; the obligation on the part of the researcher to report any disclosure of abuse or neglect, as per the Manitoba *Child and Family Services Act*, during the interview or research process. After the informed consent was given, this researcher left the incentive, in the form of a gift card, on the table for the participants, in appreciation for their time in meeting with this interviewer.

### **Field Notes**

From the moment this researcher met with participants, the environment and situational factors were noted in order to be written into field notes after the interview. Unfortunately, the majority of participants chose to meet this researcher for their interview in a public place (eight out of the 15; 53.3%) while only seven out of the 15 (46.7%) met in their homes. This poses a problem as it is difficult to fully assess the situation in which the participants live when the interview is not in their spaces. For those interviews that were conducted in the respondents' homes, it allowed for this researcher to find congruency between what they are saying and the environment surrounding them. During the interviews, the field notes became even more important as I attempted to capture the emotions behind the story. The notes try as best as they can to tie in the latent content (hidden meaning) of the situation to the manifest content (surface meaning) of their words.

### **Demographic Form**

We met at the agreed time and location, this researcher read the informed consent form to the participants, let them know that they needed to sign a copy of the consent form before the interview could begin. The signed copy was kept for research records, and a copy was left with the participants. Demographic information was obtained from a ten questions given to



respondents prior to the beginning of the interview (Appendix G). The demographic form provided the background information on the foster parents and their foster children to provide added depth to their story. The demographic form was especially necessary to acquire the information to the closed ended questions and keep them out of the interview, as a qualitative exploratory study approach centres itself on the freedom of participants to be able to tell their story in a free flowing nature. Some participants read through demographic forms as they completed it, while others did so silently. When they completed the demographic forms we began the interview.

### **Interview**

This researcher began by asking if the interview could be recorder for ease when transcribing. When the participants agreed, the recording was started and the interview began. The qualitative semi-structured interview schedule consisted of eight questions (Appendix H). The questions were designed to be as open ended as possible to allow for as much freedom as possible for the participants when answering. When necessary this researcher would probe respondents. The entire process took on average an hour of time.

### **Transcription**

The interviews were transcribed verbatim. A research assistant was used for some of the transcriptions, which had been cleared as part of the ethics submission. Each interview was given a respondent code to protect the identity of the respondent. The audio recorded files were kept in a locked filing cabinet, and all transcriptions were held in password protected word files, with participants names removed and respondent codes used. The direct quotes which are used to highlight the findings are cleaned for confidentiality as well as for flow. No context was removed, only names and places to hide the identity of the respondents and their foster child/ren,

as well as irrelevant words in their story. Unfortunately, due to time constraints there was no time to send the completed transcriptions to the participants to review for accuracy.

### **Confidentiality**

To maintain the confidentiality of respondents, the interviewees were given respondent codes. The master list of interviews and codes was kept in an encrypted password protect file, any other documents list only the respondent code. If participants' names or any other identifying information (e.g. the names of their foster children) was mentioned during the course of the interview or any other collection method, they were removed from the transcription and will not be identified in any data or written documents.

### **Data Triangulation**

The triangulation process included data from three sources; demographic form a semi-structured interview, along with field notes. Triangulation was used to allow greater and wider understanding of the topic and thus more reliability within the results. In order to complete this triangulation process the transcripts of the interviews were assessed for both free flowing themes and the overall answers to the questions posed in the interview. The data from the demographic form was compiled into charts and graphs to provide a demographic profile of participants to evaluate the wealth of information provided by participants. The field notes provided added depth to the transcriptions and the demographic form data. Using the transcriptions as a base, this researcher took the data from demographic form and the descriptions of the field notes to find consistencies and discrepancies within the information provided by respondents

### **Strengths**

Although the field notes did cause some limitations in the triangulation of the data, there were some points which were of use. Additionally, the demographic form provided a profile of

the participants, as well as information obtained from the literature helped to create a more holistic picture of how the findings fit into the larger picture. By pulling together information from the many sources it allows for more depth and understanding of how this newly obtained data impacts the current process of children in foster care with FASD being placed on medications.

The sample size of 15 participants was on target with the sample size set out in the research proposal. With 15 participants the analysis of the findings can be time consuming and somewhat overwhelming, but the resulting information gleaned is well worth the time spent.

The foster parents in this study came in with a wealth of experience, knowledge and education, allowing for tremendous amounts of information to be obtained and learnt. As mentioned in the discussion, for the majority of them, these were not typical foster parents. They were specialized foster homes with numerous years of experience fostering high needs foster children, and they provided valuable insights.

### **Limitations**

Qualitative exploratory study asserts that researchers should be aware of their biases and what they allow readers of the study to understand what potential slant may be given to the data. In this case, this researcher has been a foster parent, a day care worker and currently a supervisor for a child and family services agency. Full disclosure of my job positions were made during the informed consent process with participants, as well as my duty to report if they mentioned any information where a child was currently/ or had been abused. Because of my position and duty to report, some foster parents may not have been as forthright with information, being cautious about what they divulged in the interviews and on the demographic form. This is true in any study however, as information provided by participants can be subject to their own biases and

perceptions. Additionally, the families may not be forth coming in sharing their information as child welfare agencies have a tarnished history.

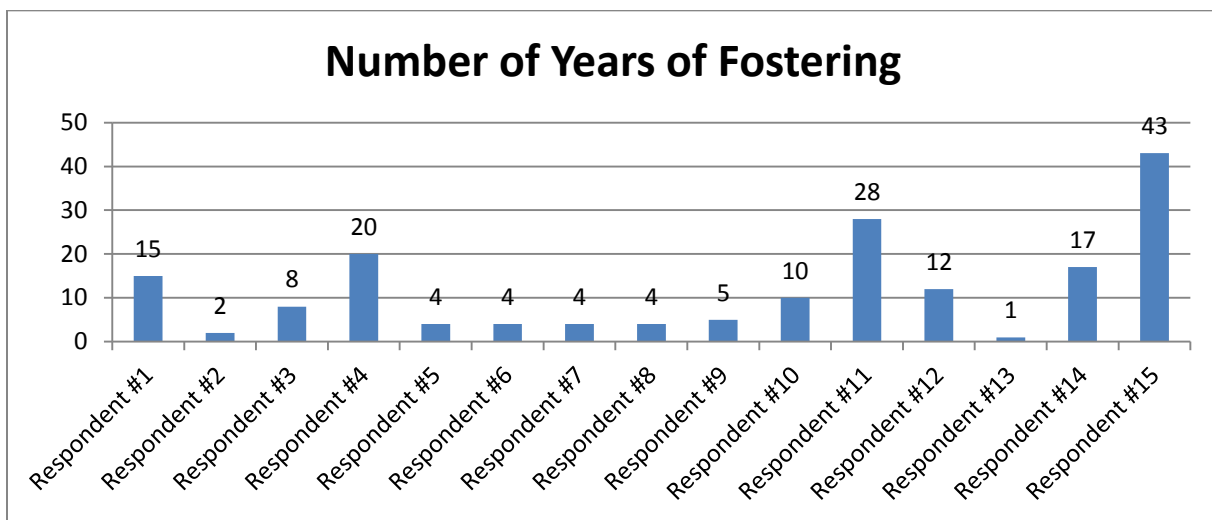
One of the major limitations of the field notes is that this researcher could only obtain a very small glimpse into their lives as eight of the interviews were out in public places, so I could not get a full picture of how the participants lived. Furthermore I only witnessed one of the interviewees interact with their foster child. This is understandable as the interview does require a quiet place to meet without distraction, and as it unknown what will be discussed it likely should not occur where the foster children could overhear. However, because of this it created an inability to observe those aspects of the participants' lives. Some foster parents shared more of their story than others, who just answered the questions. Additionally as field notes should not be taken while conducting the interview, details may be missed or forgotten. Due to this lack of information, the field notes were only of limited use to triangulate the data.

Some of the responses were not always clear or fit into the boxes that were required for the demographic form. An example of this was the question; How many children have you fostered with a FASD or suspected? Some participants were unclear about how to answer the question, whether it was referring to just children with a FASD diagnosis; including those with no formal diagnosis; or the number of foster children that they had in general. Adding some additional questions to the demographic form would provide a better picture of the experience that these foster parents have.

### **Demographic Profile of Respondents**

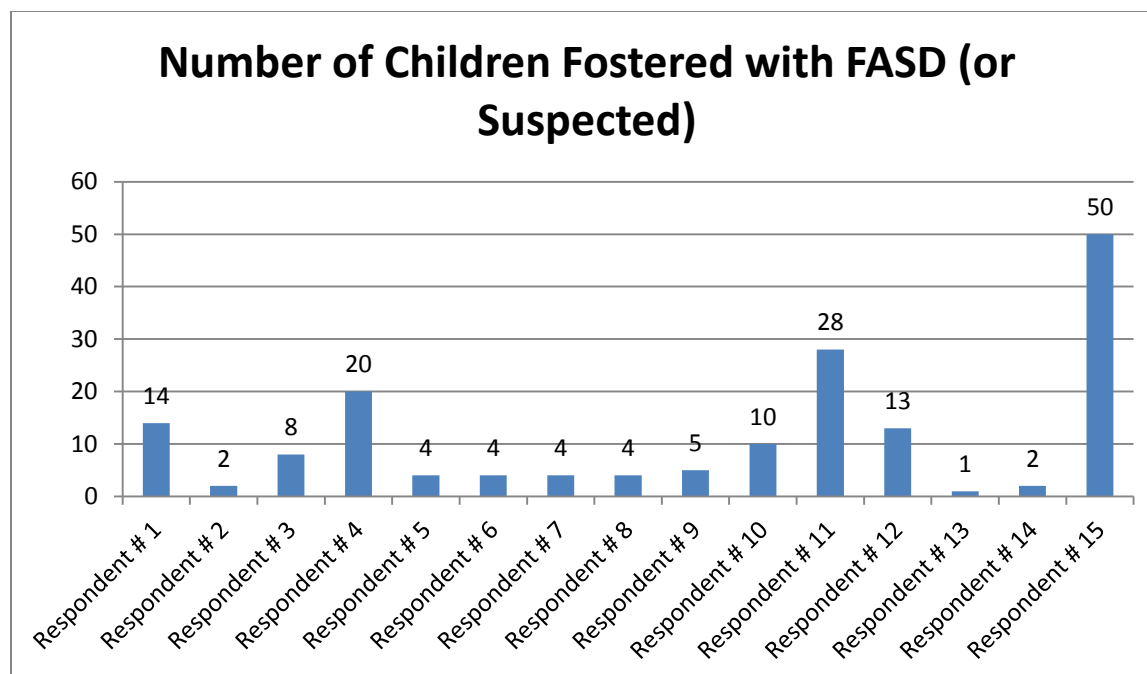
The closed ended questions of the demographic form were analyzed to create a demographic profile of research participants. Overall fifteen interviews were conducted with foster parents, one interview is comprised of two parts, interviews with a couple who both have

roles in the foster parenting process. For demographic purposes however, only the primary care giver's information is counted for the results. Out of the fifteen interviews, fourteen of the participants are currently fostering, while only one is does not have foster children in their care. The foster parents have an extensive range in their foster care experience from a few months (starting in fall of 2016) to 43 years. The average number of years of experience is 17 years, with a number of respondents having between 16 -20 years of experience.



*Figure 1: Number of years of fostering*

The majority of interviews were with foster parents that managed regular foster homes (93.3%), while one was a kinship placement (6.7%).



*Figure 2: Number of children fostered with FASD (or Suspected)*

The number of children with an FASD, or suspected diagnosis, that each respondent fostered varied widely. The lowest number of children fostered was one, with the most being 50. The majority of participants, between one to ten children have passed through their home, which can indicate long term placements. This shows that the many of the participants have a wealth of experience and expertise working with foster children who have FASD or suspected FASD.

Out of the fifteen interviews, thirteen indicated that the children they foster/ed had received a formal diagnosis of FASD, while two said that the child/ren had not been officially diagnosed.

The earliest age that a child was placed on medications was 5 years, while one child started when they were 14. The majority of children were placed on medications between the ages of five and eight, with the mode being six years of age.

Six out of the fifteen interviews have what is considered to be ‘treatment foster homes’ which require that care givers be home full time with the child. Overall, including treatment

homes, ten of the fifteen interviews are full time foster parents that work solely in the home. Five of the participants have occupations outside of the home, while also fostering. All of the foster parents that work outside of the home have professional occupations, and many within the home have held professional positions before being required to remain in the home.

The foster parents came from a mix of ethnic backgrounds, six were First Nations, two identified as Métis, four indicated a Caucasian background, while the remaining two respondents identified as black and Indigenous Latina respectively.

Determined the Need for Medication	Number of Participants
Agency	1
Doctor	8
Mental Health Worker	1
Psychiatrist	1
School	5
Unknown	1
Not Applicable	1

*Figure 3: Who determined the need for medications.*

*Note: Total adds up to more than fifteen as some participants indicated more than one source that determined the need for medication.*

Participants indicated a number of sources that determined the need for medications. Eight respondents said that a Doctor initiated the medication process, while five indicated that it was the school. Also on the list was the foster care agency, mental health workers, and a psychiatrist which was mentioned by one participant each. This question did not apply to one of the interviews and another respondent was not sure of who initiated the need for medication. The total number of values adds up to more than fifteen participants and a few indicated more than one source that determined the need for medication.

Type of Medication	Number of Participants
Biphentin	2
Birth Control	1
Celexa	1

Concerta	10
Dexedrine	2
Fluoxetine (Prozac)	1
Intuniv	1
Melatonin	2
Paxil	1
Prozac	2
Quetiapine	1
Ritalin	1
Risperidone	2
Vyvanse	1
Zopiclone	1
Not Applicable	1

*Figure 4: Type of medication prescribed for foster children*

The most common medication that foster children were prescribed was Concerta<sup>21</sup> (10), followed by Biphentin<sup>22</sup>, Dexedrine<sup>23</sup>, Melatonin, Prozac<sup>24</sup> and Risperidone<sup>25</sup> mentioned by two respondents each. Birth Control, Celexa, Fluoxetine, Intuniv, Paxil, Qutiapine, Ritalin, Vyvanse, Zopiclone were listed by one participant each. This question did not apply for one foster parent.

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<sup>21</sup> Concerta is a methylphenidate which stimulates the central nervous system, possibly resulting in heightened levels of focus and attention.

<sup>22</sup> Biphentin is a stimulant medication which may increase attention and decrease restlessness.

<sup>23</sup> Dexedrine is a dextroamphetamine which alters brain chemistry in order to aid in controlling impulses and hyperactivity.

<sup>24</sup> Prozac is an antidepressant used to treat individuals with anxiety, depression or panic disorders.

<sup>25</sup> Risperidone Risperidone is an antipsychotic drug.



## **CHAPTER THREE: Data Analysis and Findings**

### **Analysis of Interviews**

The foster parents contributed a wealth of knowledge to this study which have been highlighted in this chapter. They outlined the different processes and systems that played a role prescribing and administering medications to children in care. Various institutions, organizations and individuals; from doctors, the school system to the foster parents themselves all played a part. This chapter will provide an in-depth analysis of the semi-structured qualitative interviews using a qualitative exploratory study; respondents are guided through their interview with open ended questions, to allow for exploration of their experiences and expertise. This unrestricted space allows interviewees to fully interact with their stories and permits for themes and ideas to emerge as it unfolds (Sauro, 2015). This then allows those themes and ideas to be discovered and analyzed. In order to provide depth and further context to the discovered themes, direct quotes from the foster parents' interviews will highlight the findings. The analysis of the interviews will be triangulated with the data from the demographic form and the field notes, and will be discussed in the following chapter.

This analysis will be arranged beginning with the process for determining the need for medication, including the time frame; assessment tools and checklists; and common struggles of children in care. In order to ensure the highest quality of data results reflexivity will be used as it is important to continually be aware of personal biases while conducting research, and to remain as impartial as possible. A technique called bracketing is used to minimize the amount and impact that a researcher's biases have on the data. This researcher outlined the biases as much as possible by indicating within all initial contact documents (e.g. informed consent form, telephone script) to the participants. Within this these all biases are outlined both in the acknowledgements as well as within the data collection and the limitations. On a final note with respect to

bracketing this researcher ensured a more unbiased approach to data analysis by securing the assistance of two research assistants (which was vetted through ethics and approved) to assist in ensuring unbiased transcriptions.

Following that the main themes will take shape, starting with the influence that the school system has on suggesting the need for medication; the use of medications and other interventions; dependency created by medication; and finally, outcomes of children in care with FASD.

### **Process for Determining the Need for Medication**

There was a varied length of time in the process of placing children on medications.

*So that's when my pediatrician, who has been around for a long time he, ah, we examined some different things, did some check list and he felt the need to give him meds, well, within a week, and it was a very small dose of Biphenton.*

To a few months;

*...the process was a trial run. There were lots of mixed medications, lot of doctor appointments, and many trial runs of different medications to see which ones would actually work, and that took at least 6-8 months till it was figured out.*

To well over a year;

*First we went to a mental health worker, and then we went to a doctor, and then we went to a psychologist, and then we went to a psychiatrist and then the boys were placed on a program for critical assessment. This was over a period of a year and a half and then they were put on medication.*

Some children/ youth completed an assessment tool to determine whether or not they fit into the criteria to be classified as having FASD or ADHD. Six of the fifteen respondents (40.0%) spoke of completing assessments before medications were issued. Two of the fifteen respondents (13.0%) spoke of completing an assessment tool; one was the Conner's Parent rating scale, while the other was a scale that was not indicated;

*But once he got you know past kindergarten early stages of grade one, I knew that he was having difficulties focusing, on task. Some of the hyperactive behaviors were starting to kick in and so, I just said to his doctor, we need to look at something for ADHD. Can we get something diagnosed in that regard? So we did. With the doctor we went through the testing that he provides which is...it think it's a Conner's test.*

*It is a form that we fill out to see the child's performance at school. So then [we] went back to Dr. [name removed] and it was he who suggested maybe we can put [child's name removed] on a higher dosage to see and this dosage will make him concentrate more. So apparently, since he has been on this higher dosage I have been getting good feedback from the school saying that he is actually doing school work now, you know he gets a little irritated and stuff but other than that he is ok, he is fine.*

One was a mental health assessment;

*And I had to call the police several times. When he punched the police officer [he] had to go [name removed] to get a mental health assessment done.*

This foster parent was the initiator for the assessment;

*Let's get some assessments done so we can see where we are at. And they did the assessment. So from the time he, we knew, that he was intellectually lower than we knew.*

This assessment was through the Manitoba Adolescent Treatment Centre (MATC);

*Well, she would have had a psych assessment through I believe it was through MATC. And through that, those were the recommendations which we follow up on. It was pretty straight forward but she was having some struggles through the teen years. And that was what led us to the assessment.*

In one case it was a team effort;

*First we went to a mental health worker, and then we went to a doctor, and then we went to a psychologist, and then we went to a psychiatrist.*

In the processes of obtaining an FASD diagnoses a parent needs to admit to drinking during pregnancy.

*Like the FASD clinic wants the parent to admit to doing something like drinking during pregnancy and because his mom has passed away there was no getting that evidence from her. So Dr. [name removed] sent it back no we need proof from his mother and he would say, no his mother has passed away and he would send another requisition or whatever he did. And they would say no, we need, and then finally he said I don't know what it's going to take, to make you people understand this child doesn't have a biological mother living on this earth, but we still need that diagnosis so please do what you need to do, and that is when he got in ...*

Children in care struggle with many, many challenge when they are removed from their family home and enter into the foster care system, the findings have illustrated some of the struggles. Some of those mentioned are disrupted attachment, stealing, multiple placement, grief and loss including traumas.

A few foster parents spoke about attachment disruptions in children, and how it had affected their lives;

*... But he was very irritable and fussy and couldn't settle and had many, many, sleepless nights... They used to do the testing a children's hospital so from way back then so he was tested around three years and a half, and found to be on the spectrum, Fetal alcohol syndrome, ADHD, and attachment disorder, and anxious, very anxious.*

Leaving some child with the inability to be comforted;

*I thought of him as very hard to comfort he would arched his back like he did not want me to comfort him but I just put him so would be wrapped and swaddle him. Don't you do that with your kids we still swaddle him and I would wrap him...*

Some children with FASD may have problematic behavioural characteristics

A behavioural characteristic mentioned was that foster child/ren would tend to steal;

*...some of the struggles, I guess and like not that that would all be fixed by medication but she was awoling a lot, she was taking things that weren't hers, she took my car, there was a break-in to our house with others...*

While another said,

*...She was 16, they did things like stealing, going out and wanted to be boss of herself...*

Children with FASD may have problems understanding personal space or property;

*[The child] had some things at school regarding person space, stealing. Taking the teacher's, lots of her school supplies, so I meant if he doesn't get in trouble because I mean we know he can't always help it. They switch a few things around at school to make it more successful for him. Give him more breaks when needed, so the school is pretty good at that. Giving him fidget toys; he is allowed to chew gum if he needs. As long it is his gum not somebody else's.*

These problematic behaviours can result in, or be a result of a number of initiating factors.

Children in care are removed from their family home and often experience multiple placements. One foster parent in the study commented on her foster child's multiple moves;

*...this particular individual I have now was not initially on medication because I got this child very young and the child had multiple placements and I am his 14<sup>th</sup> placement. And I decided that I would not send him for respite for the first 10 months, so he could get use to one caregiver and not to have multiple people because he came from a shelter and there was multiple people, staff, he was young, he was four years old.*

A foster parent spoke of the loss the children experience when they are not living in their family home;

*...the only thing is, you know, is they feel a little loss at times. You know they miss their biological parents, their mother that is the only thing right now, I could say that they are missing in their lives.*

Often children that come to the attention of child and family services have experienced trauma, a few foster parent stated;

*He was three years old, and when he was seven he was taken back to the community and he was shipped around, he was sent to his dad. He told me that his dad and granny drank, and he had to hide under the blankets.*

This foster parent was speaking about the trauma a child in care would experience and not have the tools or ability to deal with the hurt that being in care brings, such as family trauma;

*...that was what I was saying too, there is a lot of talk about how we lose these children in the cracks [child welfare] they say, but these children are hurting even before they leave their home. They are hurting inside, with [regards to] their parents, with what's happening. And then when they get out there and they are placed in a home, a lot of places that I know, foster parents don't care. They are just there, not as a family or a child that you care for, for a lot of these children need love and caring, you got to show them you love them and care for them by talking to them. [By teaching them] what is right and wrong and to explain to them what [they should and] shouldn't they do. There is a lot out there that is lacking and the hurt that they [foster children] carry never comes out, they just carry it and hurt someone else.*

*...well all the time, I would say like 99% of the time these kids have come from homes where there have been a lot of trauma, and they are just trying to survive what they have*

*gone through and you think that when they do get into placements where it's safe for them and they're able to relax I mean some of the stuff starts coming out at that point right.*

Children can experience trauma when being removed from their birth home, as well as when removed from their foster homes;

*We had a meeting and I told them, how these kids were taken, they came from school and just as they got home from school. Just as they got home, the worker were there waiting, there was no preparation for the kids to be taken. The boys I told you about that were getting into trouble were just crying and he said I don't want to go back there I just want to go and visit.*

A child with FASD often has secondary disabilities which complicate their condition.

Throughout the study there was multiple diagnoses identified, including various disorders such as; intermittently explosive disorder, attention deficient disorder (ADD), as well as some had mental illnesses, and low IQ;

*As a teenager now he is playing basketball he is playing soccer he is bowling with Special Olympics because of his low IQ. Low intellectual ability so he had that to deal with as well.*

This participant spoke of her foster child having multiple diagnoses;

*She had ADHD, Conduct Disorder, ODD [oppositional defiant disorder], attachment disorder and low IQ.*

Or additional disorders;

*He had what they would call a movement disorder*

And even a skin condition;

*One thing about him too, he's always had a skin condition.*

Three out of the fifteen respondents (20.0%) spoke of low intellectual abilities of their foster child/ren;

*We already knew at a very young stage of his life that he was going to have some difficulties. He had some speech difficulties, he had some cognitive difficulties. Um, he had very poor muscle tone, he was very tiny, he wasn't growing at a proper rate, um, and*

*in fact at two years old he was still wearing infant size clothing. He was very tiny so we knew going in, there would be some problems. Um, right from birth there were some nurturing issues, and um, malnutrition kind of issues which affect his brain development, that was the other evidence that we had right from the beginning that there would be some problems.*

Although children with FASD have some challenges, there is also strength in their abilities;

*He is slow in some of his work. But, he was supposed to go for a test. But, he never got there yet. But, as I notice, like he is still slow in some of his work at school but he is quite smart in different things...*

Another challenge for children/youth in the foster care system that have FASD is that when they age out of care they have limited resources that are available to them.

The foster parent commented that child/ren with disability such as FASD may qualify for disability allowance through EIA [employment and income assistance];

*She has the support from that agency, they were able to get her on welfare, and that red ladder assessment actually has been worth its paper because they took that into welfare and they are looking at that seeing she has got the diagnosis. And they are giving her disability allowance. Isn't that a breakthrough as FASD is not considered a disability according to welfare. It's not considered, I don't understand why, it's a life time problem. And now she's got an extra \$120.00 month and her medications are paid for. So that's a beginning, we are making some breakthroughs...*

A participant stated that the transition period for youth ageing out of care needs to consider the cognitive ability they have and not to leave it up to them to be responsible for their medication decisions;

*Oh my gosh, and that's another thing right, like so I think like because I have had an opportunity to work in the adult system with cognitive delayed adults, um that have had FAS, and ADHD, and other things, that have necessitated medications, and what I have seen is that transition period especially if they don't qualify for adult services or any sort of supports like. You're putting these kids on medications, and then you are leaving them alone to manage those medications and hoping they're going to manage them, when most of the time they haven't been able to manage it. They have had to rely on you to manage their medications for them, you know, I think that it is dangerous.*

*...lack of supports with the teens. Once I think that once um they get off, um I mean once they're off from CFS a lot of times they don't continue with their care, like their care plan. It's just not there in terms of their medications and stuff like that...*

Six out of the fifteen foster parents (40.0%) spoke of the youth remaining in the foster home well after the child/youth had exited out of the care of a child and family service agency;

*You know what I, I don't think he's going to leave my care for a long time, look at [child's name removed], he's 21, he's there, and I'm going to try to take care of him for as long as I can and um as far as medication and that, well I'm thinking he's treaty. I've thought about that already, he's treaty and I'm sure they'll pick up some of the cost, yeah we've thought about it*

The main themes indicated by participants as being common struggles for children in care are; attachment disorder; stealing; multiple placements; grief and loss; trauma; secondary disabilities; low cognitive abilities; and aging out of care.

### **Schools as a Main Source of Referral for Medication**

In the interview, foster parents were asked “Who influenced the decisions regarding medication as an intervention?” thirteen of the fifteen participants (87.0%) stated that their child/ren’s school, and their behaviours at school, influenced the decision for medications. A number of participants who had multiple foster children over the years (53.3%) said that through their experience they have noticed that the school has often been the initiator in this process for many of their foster children. One respondent said;

*I am not looking at only the one [foster child] I got now, but I am sort of looking back at the other ones. How did it all come about? It was all through the school.*

Many foster parents said that their child/ren were not on medications until they started school, some starting as young as daycare, with others starting in kindergarten. By the time that they were in grade one, the majority of children were placed on medication.

One of the common threads throughout the interviews was that the need for medication began when the child/ren were exhibiting unmanageable behaviours in the classroom, and the teachers or staff at the school identified the need for intervention. Behaviours that the school



identified as being problematic were; difficult to handle in class, child not sitting for a length of time, suspensions from school, unmanageable in the classroom, and not doing school work.

Some foster parents believed that the school pushed for medications, even when there was hesitation on their part, saying;

*I just think that um, they're shoved it down our throats, right! The doctors, that's the first thing they want to give before trying anything else its medication, and the schools feel, that in my experience that all kids in care and especially Indigenous children that it's the first thing they want to do.*

Another participant said that they felt that their opinions were not considered when medications were brought up, stating;

*The doctor put him on medication, and it was very quick there was uh, no real discussion about it they just kind of put him on medication.*

Along that same line, another respondent felt that the school should consult more with the foster parents before they push medications, as she believed that if they were dealing with the child's biological parents they would involve them more in the process.

*I just, I think the school would come to the parent more for guidance, or more understanding about the child not just assuming because they're in care they're bad kids that have all these issues that need to be medicated.*

Four of the foster parents (26.7%) mentioned that they had difficulties getting the funding or resource support that they needed from the school to be able to manage their child/ren's behaviours with alternative interventions. Instead pushing the need for medications or higher dosing to control the behaviours while in school, as shown by the story one of the participants;

*So I went to the school and we met with them and we came up with a plan that maybe we could hopefully get some one on one supports in the school, but being so late in the year, doesn't look like that was going to be happening at all... [so] went back to Dr. [name removed] back so Dr. [name removed] and it was he who suggested maybe we can put [child's name removed] on a higher dosage to see, and this dosage made him concentrate more.*

Some participants pointed out that doctors, psychiatrists and psychologists are necessary in the process as they are the ones that have the authority to prescribe medications. There were a few comments about the process having been a team approach, with other systems of support being involved.

*So it would have been sort of I guess my case manager at the time, the school, the school phycologist, not the school psychiatrist, as then I guess kind of like, ours [external agency] a team approach*

Doctors also have to continually monitor medications;

*So the doctor was on top of it and we see him every 3 months, he stays on top of his weight and his height, and adjusts the medication according to his growth. Ok, so right now he is on 30 milligrams, of the Biphenton, he has only gone up in some increments but he is still a small child. Um, but he is in grade four now he is doing fabulous in school. He still has those hyper tendencies, um, but he for the most part he is doing really well at school. I am really pleased with the progress he has made but that's just for the ADHD part of it, he was also diagnosed by the FASD clinic.*

Other systems of support; such as the Society of Manitobans with Disabilities (SMD), the Manitoba FASD Centre<sup>26</sup>, the Child Guidance Clinic and Manitoba Adolescent Treatment Centre (MATC) may also be involved in the medication process. The level of involvement of these organizations appears to be on a continuum; sometimes being part of the process for one child's case, yet not at all involved in others. Overall, the two systems which were involved in the majority of instances were only the school and a doctor/psychiatrist. One particular system of support seems to be missing from the process; social workers. Although a few participants mentioned that they received support from social workers that are attached to the schools, there was little to no involvement from the child welfare agency social workers, with one respondent saying;

*I would say that's kind of true with all the kids I have had in my care, the social worker has not been, [if] she's been involved in the process it's more at the end of the process. Hey, they need to be on medications, hey.*

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<sup>26</sup> Formerly known as the Clinic for Alcohol and Drug Exposed Children (CADEC)

One of the respondents stated that she was the one who initiated the use of medication, and that she approached her child/ren's doctor to get the support and help that she needed in grade four and it was recommended through the doctor.

*Yep, yep, it was me. And I needed, like I said I was always asking for support with him and the medication is what they thought would [help].*

Teachers are very influential in a child's life once they have entered into the school system. Nine out the fifteen interviews (60.0%) mentioned the influence that teachers had in the daily functioning of their foster child in the classroom.

Numerous foster parents indicated that the teachers were on the front line for noticing behaviours from their child/ren which would be considered disruptive or out of the norm. As one respondent said;

*The behaviors that he was exhibiting at school as a young child, this is a past foster child were, I guess red flagged, through the school division and through his teachers, and then at that point they decided that it would be a good idea, once he was placed in care to put him on medications.*

Some foster parents believe that the skills and capacity of a teacher influences their ability to manage their classroom and the behaviours of their students. There are teachers that are more knowledgeable about FASD and its impact on children, and teachers that accommodate different learning needs and styles. It is often these teachers that seem to be more understanding and willing to work with a variety of behaviours. A few of the participants noted this;

*I have a teacher that understands and that is very good he understood and he was with me when I said that I will not overly medicate him. One of the teachers could handle him but the other teachers can't. Well that's their problem not ours, they have to deal with it.*

*...and it was some of the teaching too, as some of the teachers would teach it so she could remember what she was learning depending how they would present there material. That helped her as well.*

The personality of the child/ren also appears to have an impact on whether or not the teacher would advocate for them;

*I advocate for him, his teachers advocate for him, he is a neat kid he is kind hearted, a naturally kind hearted kid, he was busy but not a bad kid.*

Alternatively, other foster parents mentioned that they believe that the tolerance levels of some teachers meant that they could not manage the child/ren in the classroom;

*One more thing I want to add is some teacher tolerance levels are different than others. Some teachers are more willing to work with the child and maybe place them at the back of the classroom [if they start acting up]. If they need to stand and shift their weight, you know so they are not disrupting the whole classroom. And then you got some teachers that will say that, you know, your child is the ring leader to everything that is wrong in this school. So I think a lot is too their attitudes and what is their capacity. That's what I think.*

*So, I give him [the medication] when he is in school. But when he is not in school, I could manage him, like I know how to control him at home, so I don't give him.*

And that some teachers need to learn how to work with a variety of different children;

*No no, because like you know she grew older. To me she was learning how to behave at school without it [medication]; teachers have to know how to work with these children.*

Foster parents indicated that for some children, before they started medications, struggled with their behaviours in school, as one foster parent put it;

*...if she skipped a day or something, like if she pretends taking her medicine she didn't, she was completely out of control. Chasing teachers at the school with pencils, causing problems at the school; I was getting phone calls and emails I'm telling you, almost like on a daily basis. Then for a while she was taking her medicine on a daily basis, she was doing much better.*

After some of the children began taking medications, teachers noticed an improvement in behaviours in the classroom, often mentioning it to foster parents;

*So, after the medicine it improved, it improved, at the school they would focus better. With their homework or when the teachers was talking to them, or teachers aids, um they got little better social life too, cause they started having a little more friends, because behavior improved.*

*But when I finally just threw in the towel and said okay, they can go on Concerta, it made a huge difference in both of my sons. One of my sons, the oldest one, went back to school in the fall, and the teachers who taught him previously said, what did you do with that other one [same child], I like this one so much better he was so different and it made school so much easier for them.*

With some foster parents getting less notes or calls from the school;

*I don't get notes home anymore, I don't get calls from the principal, they, the kids are well behaved they are involved in everything. In fact the teachers like them.*

Or not dreading parent teacher days;

*It has been a positive experience for the boys at school and for their teachers and, for me as well because I don't dread parent's day anymore.*

For children that are on medications, teachers also can play a role in monitoring if they particular type of medication is working or if the dosage is correct. As one respondent added;

*...now that he is on a higher dosage, I do have emails to show from the teachers, and now that he is on a high dosage I have gotten some good emails saying that he is actually doing his work. In school he was leaving the classroom on his own and not listening to the teacher, and she said she has a classroom of 18 kids and he is wandering off, it is a safety thing for them [the school] so with them being on a little stronger medication, he is doing well, or better.*

On the other hand, teachers also noticed adverse effects that medications had on children;

*During the time he was on Concerta, the doctor had changed him to Bifenton but it only lasted a week because the vice principle, who was the resource teacher, said no, no, no, no something is wrong here, this is not the kid we know.*

Participants pointed out that there needs to be communication between the different areas of the school as well as with the foster parents to ensure higher levels of success for the child/ren;

*The teachers, the teachers' aids, the workers, we all have to work together and communicate with the child and help the child.*

*Well I think we would follow through; anything sent home, good communication with the teachers.*

A few foster parents mentioned that they believe that the school system needs to find ways to adapt to the difference in learning styles and behavioural characteristics;

*Oh, her medicine is not working, but I said we have to work altogether too; there is no medicine that will fix all things. We have to communicate, and to see what the child's needs are; does she need more help with the school. Teachers, aids or classes need to be modified; we do not want to set them up to fail. Right? We want to set up the children to succeed, so we all have to work together; the foster parent, the biological parent, the social worker; to make it better and easier for the child, because the pill is not going to work by itself.*

One foster parent mentioned that she believes that teachers and staff in the school system need to have more education around FASD;

*I think that we need to educate the people in the schools to even acknowledge that Fetal Alcohol Syndrome exists. These kids are not being willfully defiant, even this day in age I deal with a lot teachers that think it's an act they don't even believe it's true; and I think that we as a society need to get more innovative in how we approach kids and get to know them as individuals rather than paint them with one big brush.*

But that the limitations of the school budget might get in the way;

*If it's needed [medication] I don't disagree but I think that we go to it far too quickly. I think that schools there budget is limited to right; everybody is at a financial crunch. I have a wish list but I don't know if it could become a reality. You know, so we have to make the best of what we got right now, and as a foster parent I try to be as innovative as I possibly can because I can't fix the whole big problem but I sure can try to fix what is going on under my own roof, to make it as best for the kids that are in my care.*

But if additional funding for supports can be secured;

*She had pretty good teachers, was at our community school so everybody was pretty on board and then in high school she just had some amazing funding, she had an EA [Educational Assistant], like she was able to [succeed], there was just such good supports.*

*His teacher was so good, she sat with him and told him what we were going to do...He has his own computer in the school too, all from the school, the department of education. He is a kid who got a lot of help along the way.*

Respondents said that an important piece to their role as foster parents is to advocate for their children;

*When I have children with FASD, when they come home from school I go and talk to them, I ask them how was your day, if everything is ok, or did anything happen that bothered them. So, you know if something at the school had bothered them, I would contact the school resource teacher or the office, I tell them this happened and it bothers my child, [and ask them] can we do things differently?*

One foster parent that had worked in the education for years said that she has seen children get stigmatized when they are in care and enter the school system, and she did not want that for her child. She said;

*...you can see kids in care on how they are stigma, but like I just didn't want that for her, ever. So I was trying to make her be, just as normal as anybody else.*

A few of the respondents mentioned that they already had, or were trying to get educational assistants for their foster children, seeing the benefits that having one gives;

*...she got funding and so she had like and EA...*

And one-on-one support;

*He had to go to a daycare, to get him ready for the social skills aspect, and get him ready for school [he had been denied entrance into kindergarten] because he couldn't learn his alphabets and his colors. I would work with him at home alone, but he couldn't retain so he went to the social worker and myself, we really worked for him to get him one-on-one support. So he did get level three funding, after a long battle, and got his one on one support. To get him ready for kindergarten at age six. So he started school one year later and he is one year behind. Uh but he was ready, he knew his colors and his social skills were a little better, he could say thank you and please.*

The foster parents listed a number of important areas in connection with the school being the main source of referral for medication which are; Children in care need more support services in school; teachers flag the child/ren; teachers understand; teachers cannot manage; teachers notice a difference; communication with school; need a different classroom model; school budget limitations; and educational assistants (EA).

## Use of Medications and Other Interventions

The use of medications for the management of behaviours related to FASD can have both positive and negative results. This theme from the findings identifies the positive results of medication usage, along with the side effects and concluded with the alternative interventions which foster parents have identified as being helpful.

Although the school influenced the decision regarding the use of medication as an intervention, six out of the fifteen respondents (40.0%) stated that they saw positive results. In those who commented that they saw some advantages, they noted that the child/ren can think and focus better in school, as well as being able to make better decisions;

*Oh, medication has helped him so much. He's able to, he's good in school, like he's able to sit and read or he's able to do his homework.*

*As a school teacher, well, I am not a big medication person; however I have seen it effective in children just for social pieces, impulsive pieces. I have seen changes more at the school piece I think, than at home, in the most part. I am just saying in general we have been ok, um, but certainly for the school piece it has helped... the children, that's what I have found*

Better in school;

*Well my life at home was actually was not too much different but the life the boys had at school was extremely different. They spent lots of time in the principal's office. My youngest was not even allowed to sit at a sharing circle because he couldn't sit quiet. They would take papers, they would push, they were rowdy, they didn't get good marks and after the meds started they are getting...they are doing much, much better in school.*

The child could not sit still without the medication;

*He is the type of person who just can't sit still. And he has always been like that, but when he was in school and young enough that I was able to medicate him and he listened.*

Another responded stated the same;

*He was on a slow release stimulant and that seemed to keep him calm enough, he just had a little small dose, calm enough so he can pay attention and he could sit on the carpet and listen to the story that was being read.*



The medications not only had an impact on their behaviours in the classroom, it also improved their social skills;

*...the school noticed, and he you know grade one and grade two he did really well. Not that he had a lot of play dates afterschool but he was then invited to birthday parties, things like that were really positive.*

One foster parent later shared that a part of the success is attributed to working as a team,

*...it is important to have the support of the social worker and the school and the resources the school has to offer; for example the school psychologist.*

A few respondents expressed the emotional difficulty they experienced when making the decision to use medication as an intervention;

*When you first have to consider putting them on anything it is a very tough decision. It is very hard to admit to yourself that your child needs help and that I don't have the choice to help them. That's very that's a hard road to cross. That was hard for me, especially with [child's name removed] in grade one when [child's name removed] I knew that he needed help and the doctor just sat me down and said, if your child had cancer would you treat your child, I said of course I would. Then why is this different, what makes this different? And I said I don't know, he is not sick, [doctor] but he is got um I am trying to think of the correct phrase used and he said, he's got something missing in his brain.*

Another foster parent also did not like to utilize medications;

*...well I don't like giving medicine to anyone but if it is going to help them to have a better and decent life and it is better to improve their social life and make things easier in the school so they don't fail then I guess it is good thing to do. Take them to the doctor and if they need medicine, and it is going to help them then I think it is the right thing to do.*

A few participants said that medication is not for every child;

*Like not only to do with their FASD stuff, like they should not be given antibiotics every time they sneeze and cough either.*

This responded did not need to change medications;

*I have never tried to change it because it worked. You know I said to the doctor, if this works we are staying on it, we are not going to bounce around because I have been through that with one of my other children. I have been through several different types, you know Ritalin, Concerta, there was even something else, before we hit the Biphenton and that's what worked.*

This foster parent noticed such a positive result, she felt she did a disservice to her foster children to not try medication earlier;

*When, these last children were placed on medications when they were eight and nine years old, and I will tell you I did a huge disservice to my foster children because, I, personally, I don't like medication, so I didn't put them on medication, one for two years, and the other for a year. Because, I thought we could work through something else and we would have a reward system and we would do all kinds of things. But when I finally just threw in the towel and said ok, they can go on Concerta, it made a huge difference in both of my sons,*

One respondent believes medication has its place and not to stop there;

*So is there a place for medications? Perhaps maybe to get them through that period of time, yes. But then what happens after that? I think we're not, we're not doing them a service and we just stop at we give them the medications and there is some improvement and then we just don't think about it or look at the situation a little bit more.*

In working with system, it makes it easier to access supports when you know about how to work within systems;

*I have background and was teaching where is if you don't know anything about any of the systems right... you know about the system it sure helps, when you are looking for stuff for kids like the supports, cause you kind of know, but if you don't know anything about any of that then it is hard, for sure,*

But there can be barriers to accessing those systems;

*A foster parent generally wants to do good, but doesn't know how, and then you have a system where you know you have a medical system and where a lot of times accessing the system um, services you know they take time either to set them up or you know, get into them. The other thing is, if the child doesn't buy into it, and a lot of kids don't buy into you know meeting with a psychologist or whatever it is then you have another receipt for disaster right.*

*...or you then have the school piece it's you're dealing with like, these kids are dealing with various systems and they all have their expectation of the kid...*

As with most medications, those used to manage FASD and its related conditions are known to have side effects on users. This statement is true for those children/youth whose foster

parents took part in this study. Twelve of the fifteen participants (80.0%) mentioned that they noticed at least one side effect from their children being on medication.

Seven of the respondents (46.7%) stated that their foster child/ren exhibited a loss of appetite while on the medications, as the following statements exemplify;

*He just won't eat anything. He won't eat and says he can't eat. But like I said when he doesn't take his medication he will eat and eat and eat, you know?*

*The eating, was the other one, seeing the lack of appetite, so we went from like a large appetite, wanting to eat everything in sight all the time to just having to remind the child you need to eat.*

*He wants to play on the weekend and it also takes away his appetite, when he is on his meds, he does not want to eat, and he really likes to eat.*

A few foster parents indicated that they learnt to monitor how much food their child/ren were in taking to ensure that they at least had sufficient nutrition;

*...there is not actually FASD medicine but there is medicine that can help with the behaviors, they can lose their appetite, or sleeping. It is based on individual children, you have to keep an eye on them on what the doctor gives you, medicine. I always watch, if they eat less then what they are used too, or if they eat more then what they are used too...*

An added effect of the child/youth not having an appetite is that they would also lose weight, and in some cases that weight loss may have been extreme. One respondent told the story of her foster child;

*When he started, he was a chubby little child, if you saw him now you'd be shocked at how thin he is. He's very thin because, and the doctor, he just went to the doctor's a few days ago, he sees Dr. [name removed], she said it's from the medication.*

Even earning him a nickname from his sibling;

*His sister calls him "Twig".*

Three respondents mentioned that their foster child/ren had difficulties falling or staying asleep. One foster parent said;

*...he was having a hard time sleeping because of the medication...*

To combat this problem some children were given sleep aids, while other foster parents would not give them the medications when there was no school, so they would have a better sleep.

A few foster parents had concerns about the child/youth overdosing on the medications, or that other children/youth in the household may get their hands on the medications because of stashing. One respondent said;

*It scary, it's a huge responsibility as a foster parent to make sure his medications don't get in the wrong hands, cause I had some kids with suicidal tendencies and they have manage to get their hands on pills.*

A few participants mentioned that the medications which their child/ren were on had negative interaction effects, or that they interacted adversely with their body chemistry. One interviewee stated;

*And the side effects were, that they weren't working together. So it wasn't managing the behaviors that they were supposed to be managing for the child.*

Two of the respondents (13.3%) indicated that they would see mood changes and irritability in child/youth when they were on medications;

*...you know he gets a little irritated and stuff but other than that he is ok, he is fine.*

But even more so when they dose was wearing off;

*I also saw the mood change when they are coming off the medications; the medications are starting to wear off...*

Only one responded noted their foster child found out he get high off the medications. She explained the difficulties that she had when one of her foster children figured out that if he chewed his medication that he could get high. She said;

*Even though I controlled the medication I gave him every morning, he got very smart and he would hide it in his mouth and if they chew on it they could get high on it. He kept a*

*few of them where they [the school] had to call in the ambulance, because he was so high in school from it, from chewing his medication.*

After a while, an external community service agency made the decision to take him off of the medications as they were not accomplishing what they were supposed to, namely keeping him focused in school. Getting high of the medications ultimately had dire consequences as she stated;

*Cause he was already introduced into drugs. He already knew how to get high from his pills. He then just got into bigger and harder stuff. And where is he now [in jail].*

When speaking about the use of medications and other interventions, respondents indicated a outcomes; positive results of medications; side effects of medications; loss of appetite; loss of weight; trouble sleeping; concerns of overdosing; negative interaction of medications; change of mood and irritability; extreme side effects; zoned out or zombie; concerns regarding medications; alternatives to using medications; structure; combination of alternatives with medications.

### **Dependency Created by Medications**

In some cases the side effects of the taking the medications can be extreme, as in the study three out of the 15 respondents (20%) reported fairly severe reactions.

One of the foster parents spoke of the digestive problems that she felt was created from the overmedication of her foster child. She said;

*A lot of his medications gave him some very severe side effects including stopping the gut from moving at all, he would be unable to eat.*

Sometimes the nausea and constipation was so bad that they would have to take him to the hospital;

*[The doctor] would listen to his abdomen, and there was no sound and he looked at all his medication and he said this is a lot of heavy medications for such a young child.*

Six of the fifteen respondents (40.0%) said that they found that their foster child/ren appeared disconnected at times while they were taking the medications. The foster parents used terms such as ‘zoned out’, ‘Zombied’ or ‘spaced’ to describe the behaviours of the child/ren during those periods of time. The following quotes highlight their experiences;

*How would you describe that they are zoned out, they look like zombies so, I would have probably monitored the effects, on their medications.*

*Ya, I have seen some kids that were zombied right out because they had too much medications.*

*... “Zombie like”, and so it didn’t seem like that child had a personality or spirit, it just seemed like the child was just going through the motions of the day.*

*...I had a child that was given to me, and he was on Ritalin and he said that it made him feel like a zombie and it made him feel dopey, and everything and I really didn’t want that to happen to my other children*

One foster parent stated a concern regarding administering medications that had not been tested with long term drug studies on children;

*And as far as it goes for kids getting these medications, I guess I am always trying to be open to what is best for the kids. And it’s scary because I told you earlier none of these [medications] have never really been tested on kids. I always, we all want to do what’s best for these kids to help these kids have a good life.*

Nine of the fifteen participants (60.0%) mentioned alternatives to using medication, or alongside medications, for their foster child/ren.

Structure, repetition and discipline were mentioned by a number of foster parents as methods of working with their child/ren with FASD. One respondent said that discipline is an important factor in parenting and something that can be sorely lacking with even children who do not have FASD;

*I have noticed when I go somewhere I can tell, even with children that are not FAS but like you know, there is a lot of lack of parenting. It is not disciplining their little kids when they are small, in public or when you go somewhere.*

Repetitiveness and routine are also important;

*I guess what I did with them was, I had is lots of structure and repetitiveness. Repeating to them a lot, in a routine, and I think that kind of help him not being on medication, the expectation and what to expect I guess.*

And reminders;

*...another thing you have to keep reminding them. All the time, just constantly but I did, what I did was I use to put like brush your teeth; I bought them it a teacher store [a visual chart]. Where they teach kids, to brush their teeth and wash their hands.*

Another foster parent taught her child a deep breathing technique;

*He says I will take some deep breaths, he is very good at doing what you would suggest because he has learnt it, and relax and tell yourself what you are going to do, take some deep breaths go and change your activity. Go and do something quiet, he has big headphones because he has to block out external noise. And then he will listen to his music and he will sing and be ok, so that is how he manages, he is a neat kid.*

Even chores can play are role;

*Like I said before, the meds will last throughout the school day, so when they get home at the end of the day, the meds are starting to wear off. So you can start to see some of that loudness return and some of that hyperactivity kind of behavior return and so we just give them things to keep them busy. We have sometimes homework but they also have chores, whatever it is it is organized you know like [child's name removed] will say to me, I think I need to go clean my room.*

And above all, patience;

*Well, children with FASD needs a lot of work you have to be really, I think the most thing you need is to be patient because children with FASD reacts with things differently and do things differently, then we do. Sometimes it takes them longer to understand or it takes them longer to figure out how they are going to do it, so, patience is the main key, and communication. Because they get frustrated they get upset, and sometimes they can shut down, so you have to really be patient with them and talk to them a lot, on regular basis, see what is bothering them, what you can do to help them.*

A number of foster parents said that medications may have their place, BUT that they should not be the only intervention which is used. Children also need to be taught skills to help them learn and self-regulate, medication could be used to help them stabilize but should not be seen as a replacement for education and skill building. As one respondent put it;

*I have mixed feeling about medications. I think on the one hand medications in certain situations are needed, and I think for a period of time. I think for me, medications are supposed to be given for a period of time to allow the person time to build skills in order for them to be taken off the medication in order to survive, live and thrive without the medications. I think what happens though is we miss that other piece, we put them on the medications and then we think you know it's kind of fixing the problem and then because a lot of times the behaviors maybe subside [but they are still there].*

And that foster parents need to think about the long term;

*A lot of times people just kind of stop there without thinking what are the consequences, what are the ramifications of keeping kids on the medications long term.*

A variety of foster parents said that people need to understand that part of acting out or having a lot of energy is part of being a kid;

*Maybe ah, like she started off, she was 13 years when they are around 13 doesn't matter if they are FAS they still act up. If they had something cause their bodies are changing. Maybe that is what is doing with that girl as it helped her, with their hormones and everything.*

*I feel now with the younger one, when they try to up the medication again because he was acting out in school. Part of it is he becoming a teen ager and I find that it is all normal behaviors. We are going to have some behaviors as they are growing older ... Those are normal behaviors we will have to deal with as they become teenagers.*

One respondent mentioned using nutrition to help regulate;

*Oh that's right then she found this, it is not a drug it is some kind of, a natural thing she give that to her granddaughter, now that girl is just calm. And every time she would run out here and ask granny when is that stuff coming again. She told her grandmother, I am getting feeling all hyper up again. And she would drink that stuff.*

Another foster parent mentioned the importance of the child having someone that they could talk to. Someone neutral, someone outside of their foster family and social worker;

*If they could talk to another person, somebody who is not connected to either and that they can tell them how they are feeling and they usually don't know why they are feeling that way. But you know it is a teaching in its own, it's a teaching mechanism for them, for kids to be able to start voicing all these things that are going on in them.*

An important finding in the responses is that foster children need the love, comfort and support of their foster families. They need safe environments that they can thrive in;



*Because he is a kid who really benefits from everything you'd do from a tactile perspective. So for a person like me, [occupation removed] he would like the weighted blanket, I knew he liked a lot of pillows in his bed, a lot of blanket; building a fort, when he was on the bottom bunk. We would put a curtain around so he would feel screened in. So he needed to feel that, but he also needed to be held and comforted.*

Or the environment at home;

*Say for example something simple like the light bulbs in the house, when you think of a kid with FAS, and how there are certain types of light bulbs that will cause some discomfort or stuff like that.*

Or even their clothing;

*...even clothes perhaps; maybe the material or just little things like that that perhaps may be some foster parents may not necessarily think of. So you'll have kids that are demonstrating all of these like behaviors and then you have a foster parent generally wants to do good, but doesn't know how.*

The need for nurturing due to attachment;

*I will give him what he missed and put him in the blanket and swaddle him and he was still using a sippy cup and I let him continue to use a sippy cup; until he put it away.*

Sometimes it is just about finding what they like and spending time with them;

*There should be other ways, what I did was talk to them. Talk to the child about what was happening at school. I would then help her to focus on somethings like puzzles she really liked puzzles. She would sit there for hours doing a puzzle.*

*With medicating children, I don't think is appropriate, I think society is too quick to label our children for whatever reasons. I think there are different ways to deal with a hyper activity of a child, whether that is finding different activities, soothing activities, quiet activities or activities that really tire them out like running or baseball. All those types of things there are different ways to get that energy out of a child rather than really pushing down and child to give them medication. That's what I think.*

Most of all fight for them;

*I get so emotional thinking about this as it has been a long struggle, it has been a fight. I have fought with the school. I fought with the doctors about trying to help these children. But something good will come out of it. That is what I am hoping for.*

Six out fifteen interviews (40.0%) commented that their child became dependent on the medications and expressed the child/ren reliance on the medication to help them. This

respondent spoke of her foster child/rens' dependence, and that if medication is not paid for when they age out care that could have some negative results;

*I like that they can focus in school, which is good they should be able to focus in school cause with my little one, he says he cannot focus in school. But now they get dependent on it, he says grandma I can't focus, I need my meds so I can focus in school. And same thing with my foster daughter that I have, she has been on medication since she was five. And when she turned 18, she took her prescription in and they would not fill it, because the agency said they will not pay for her medication any longer. So what she did because she was so addicted to it already and so dependent on it that she cannot focus unless she has her meds that she started stealing my younger child's medications, you know in order for her to function because the agency would not pay for her meds.*

Child/ren and youth begin to feel when they need the medicine for help;

*You mean whether they needed it or not, ya like this one, he knows he needs it because he will say the TA [teacher's assistant] in school he will just look at her and say, he is on a PRN [pro re nata<sup>27</sup>] during the day, Quetiapine, he gets so anxious. If it's a subject he is worried, and he says sometime if they ask a question, everybody puts there hand up and he has no idea what they are talking about and he get anxious. He gets so anxious he starts hyperventilating. Rather than he start, he looks at his TA and says I think I want my PRN, when he is at home he doesn't need it, as he will go and change his activities like shoot some basketball.*

One respondent would like more information given to a foster parents, child/ren and youth regarding the effects of the medications;

*To create dependency, ya, I think so and personally I think that we are doing a disservice to our people because we're not a lot of times, these kinds of medication, um, we don't really explain to them the side effects like properly. Like really explain to them or even when they're going through these changes explain to them what these medications are doing to them, um, what can happen to them if they're doing you know street drugs and you know [while using] these medications, um you know the importance of perhaps taking the medications consistently and at the, at the same time every day and everything.*

This participant realizes her foster child did better when he was on his medications;

*My view regarding medication... it is really needed I really think it is needed, even when he is on this higher mg he is better, he's better. And with the sleeping aid he was having a hard time sleeping because of the medication so, Dr. [name removed] gave him the sleep aid to help him fall asleep and uh, he is better.*

This foster parent was also in agreement;

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<sup>27</sup> Latin for 'as when needed'

*I have a couple of other children now that absolutely could not survive without medications. Can't survive a work day or a school day without help and so, ya, I can see how they need it and how they need it to function and the ones that aren't on it, should be,*

But creating dependency may lead to harder drugs;

*So I, my view, and I've seen it I mean I've talked to adults too that have been in care, when we talk about my seventeen year old I think of her mom and I think of her specifically because I've talked to her and she was in care. Again medications, to treat stuff and then got booted [out of care] you know when she was 18 and um, when she already had the dependency and but didn't have the skills to manage any of those things. So unfortunately for my seventeen year old, her mom is now, like highly, highly addicted to other things and really for her, when you talk to her she will tell you like it started with just taking regular medication.*

Another respondent stated;

*I think it's perhaps that is part of the reason, why you know we have so many kids and I think that there are many young adults that are depending on substances. I mean there's trauma and all of that, but I think it's a habit and so if they are learnt that taking a pill makes them feel a certain way I think that pattern has already been established and so when they're an adult, it just to me, it just makes that jump a little bit easier.*

Three out of the fifteen participants (20.0%) stated that the child/ren was either dependent on a substance or used illicit drugs to help calm them;

*...It led her down a path of drinking cough syrup, or taking a box of Gravol. It was just horrible, and she found when she takes her Concerta, she could stop and think...*

*Uh um, I have got another son who, was on medication but he didn't like the fact that it took away his appetite, he didn't like that feeling, um, and honestly he has found another way to deal with it, he smokes weed ... it all depends on the individual, I think, ultimately.*

Sometimes stealing in order to get the medication;

*... That is a narcotic I said, and you stealing his meds so you could focus, that is wrong. That is stealing ...I know, I said why didn't you tell me the agency was not going to pay. I would have paid them for you and I would have got after them to reimburse me. But you do not steal... for those drugs.*

Two foster parents indicated that their child/youth needed to be admitted to receive a medical stripping<sup>28</sup> due to the effects of the medications. In the case of both of these youth, they were both about 12 years of age.

One respondent spoke of the need for the stripping process to be done slowly to avoid causing severe damage. While another participant explained the extreme reactions that the medications were causing for her foster child; including allergic reactions, a movement disorder, losing weight rapidly, and loss of functionality. At the point when he was taken into emergency, they were concerned that he would have a seizure, so they opted to clear out his system of all of the medications. She said;

*At that time they kept him on the medical ward for a while and when they cleared him medically they sent him to the psychiatric ward, PY1.*

Five of the foster parents (33.3%) said that even though their child(ren)/youth are on medications they only administer them from Monday to Friday, taking a break on the weekend. One parent wanted their child/ren to “eat well and have a good sleep over the weekend”, while another felt that medications were only needed for school. Three participants in speaking for their child/ren and how they felt on the medication, with one child asking for his pill as he, “struggled to hold himself together”.

While two other children did not want to take their medications, as one foster mother put it;

*...he doesn't feel like he can run as fast [while he is taking the medication]. So on the weekend he doesn't take his pills and he runs fast and eats whatever he wants.*

Nine out of the fifteen interviews (60.0%) have experience refusal from there foster child when administering medications.

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<sup>28</sup> When an individual is admitted into a medical facility to remove the medications from their system in a controlled environment.

*I have had refusal in the past, once again, um, and the side effects were, that they weren't working together, so it wasn't managing the behaviors that they were supposed to be managing for the child,*

This foster parent felt frustrated when her foster child refused to take the medication;

*I think in some cases it has really been good to see it make a difference and it has been helpful. It is frustrating when the kids don't want to take the medications.*

One respondent stated her foster child stopped taking the medication once she was an adult;

*They just stopped it, they decided once they turned 18, they're an adult now, and they are making adult choices. And you know I can suggest, but I can't make them.*

This young child had a difficult time swallowing the medication;

*He refused? I don't know, he would always have to take it with apple sauce because he couldn't swallow the pills so that was a little bit difficult for him. But he did feel the medications were helping him, so yeah, but he did refuse a lot of the times.*

This participant felt that it would be a better choice for the foster child to take the medication but they did not;

*... because all of our children have been affected in some way by drugs and alcohol. Um, some of them are on medications and some of them aren't. The older ones have chosen not to take it, and they may find later on in life that they do need it but that would be their decision. Um, I can see the difference, I mean I have a 21 year old boy who is very hyper and cannot sit still, he has to be busy all the time he just can go to 0-90 in seconds, um, and so I can see for him the benefits of being medicated. And he is not.*

*...well my child decides every weekend that he is not going to take it,*

A foster parent decided, not to administer medication;

*I would say probably around the age of 10 or 11 and we just stopped giving him medications, you know it was the schools issue to deal with his different behaviors and medication wasn't the way to do it.*

The youth decided she was not going to take her medication;

*Ok, but those are... I have another one, but she is going to be aging out of my home in a little while. She wants to do independent living. It's a funny thing now that she is working full time and is not going to school anymore, she doesn't take the Celexa and she doesn't take the Biphentin. It's amazing eh.*

One respondent estimated the ages of the child/ren that experiences of side effect on medication and the age where she believed youth start refusing medication.

*Well with the side effects, I would say young ages eight and nine, I want to say, in terms of the refusal I would say in their teens like ages fourteen and fifteen.*

Ten of the fifteen respondents (66.0%) said that medication was over prescribed and/or did not want to overmedicate;

*...the last resort absolutely the last resort, I think it's over prescribed.*

*Yes, yes, um, but there is not really an extra medication for that, and I am don't really want him on a bunch of pills and neither does Dr. [name removed] I am happy with the Biphenton um; it's an eight hour time release so it will last the whole day at school. When he comes home he doesn't need to be medicated again, I don't believe that should happen unless we have an outing in the evening that he is really excited for and just can't make it through without some help. And even then I question it.*

For a number of children mentioned in this study the side effects of the medications taken to manage their FASD were extreme. Foster parents mentioned a number of concerns that they had in relation to this matter being; dependency created by the medication; dependent on substance; medical stripping; no medication on weekends; and refusal.

### **Outcomes of Children in care with FASD**

There are numerous positive and negative outcomes for children/youth with FASD who are on medications that are in the care of CFS. This theme explores the concepts of family, suicide, homelessness, incarceration and the idea that caregivers need more training.

Twelve out of the fifteen respondents (80.0%) spoke of the foster child staying connected to their foster family after they have aged out of care. This relationship appears to be reciprocal and numerous foster parents have indicated they view their foster child/ren as a family member;

*When she was living back at home with me almost all my foster kids, even after they have aged out, they come back home...*

*In our home we don't think of them as leaving care like we have another girl that's still a part of our family that she's been gone for eight years and still comes home for holidays and stuff.*

*...and then she became an adult, she stayed with me almost two more years after that.*

*...But oh ya, we do our best, they are family here.*

*...it's really hard when you bond with these children, it's hard when you had them for so many years, you feel like they are your own ...*

As one child stated to her foster parent;

*You're my mom...*

This respondent said it is important to treat the kids as your own;

*I try my best I treat all kids that come in my home as if they are my kids or grandkids. I have five grandkids and they all have to respect them as though they are one of them. There is no, this child is a foster child and this child is a grandchild we don't have that, they get invited to everybody's birthday and what not...*

As often the child/ren do not have family to go back too;

*She would come back to me, the foster parent, and she didn't have a lot of family... I am there mother she did not have a lot of family. I find that with a lot of these kids. We become their primary family if you have them especially for a longer period of time ...*

*Both his parents are deceased, yeah so tragically, tragically his dad was just killed in the community by his brother, tragic lives these kids have had...*

One responded stated she had adopted her foster child's, children;

*Yes, we have adopted her children.*

One foster parent spoke of the needs children have to be loved and that she had witnessed in her experience that not all foster parents are on board to being the family that a foster child would need;

*..they are placed in a home, a lot of places that I know, foster parents don't care they are just there, not as a family or a child that you care for. For a lot of these children need love and caring, you got to show them you love them and care for them by talking to them.*

A respondent speaks of a previous foster child and his need to belong; he is now an adult and keeps in touch;

*Well I know he is older and he is not on any medication. And to me he uh, he's um, very much focused in life, loves to work every day. He just wants to take care of his family. He did get involved with the law, but um what do you call it, his reason to that was, he wanted to be a gang member he wanted to belong somewhere. Any child or young person wants to belong somewhere. He has kind of outgrown that and like I said he is now focused on family and work, and moving ahead in life.*

This responded stated both their adult foster children enjoy coming back home;

*...ya, every one of them, every one of them, we have been blessed in such a way everyone that come into our home has stayed. We haven't had that open door effect happening at all, everyone has stayed by the grace of god we have become a family. And so now that [child's named removed] is coming back, he will come back every year when the spring shut down happens for his work. Just knowing he wants to come back first and for most, and he is comfortable when he is back it's not like I have to go to my parents' place cause I have nowhere else to go, its oh I get to go and see my mom and dad. You know and for [child's name removed] as well she is our oldest. She is 24 this year and she will always want to come back especially at Christmas. She wants to come and have a visit just stay in contact with us.*

The foster parent spoke of some struggles her foster child/ren had experienced regarding family visits and how much stress this can create for a child;

*...because you know, there would have been somebody to diagnose and somebody to really look and really see, what exactly was happening and see what is this because they have the baggage of what happened before they came into care and they have the baggage of trying to deal with family visits and how everything is going and their loyalties. They have so much to deal with, you know, like if they love a foster parent too much is that being disloyal to their own parents and if they would rather stay in their foster home rather than going to live with mom and dad, is that being disloyal or is that being a survival type mode you know, they have got a lot of stuff to think about...*

One participant continues and states they needed each other as much as the children in their care needed them;

*And we needed a forever family too. You know it was not just them it was us too, so we do the best that we can every single day... So, family is family no matter what is looks like or how we got together we are a family.*



Two of the fifteen respondents (13.0%) spoke about suicide, and how as foster parents they needed to be aware of the issue, always making sure to be on top of medications;

*It's scary, it's a huge responsibility as a foster parent to make sure his medications don't get in the wrong hands, cause I had some kids with suicidal tendencies and they have manage to get their hands on pills, because they found a stash that was hidden on the window sill. That they found before I did. So sometimes it is really scary. We [foster parents] really have to be on top of that.*

Also noted in the stories of the families was an historical event of trauma where the mother died by suicide and the daughter also attempted suicide;

*...on a Sunday her mom goes and gets drunk. The next day, gets put in a cell, and she hung herself, she killed herself...Yeah, [child's name] was just diagnosed, that's the 16 year old. She's on antidepressants because she's tried to commit suicide about three or four times, only because of this depression that just kind of takes over.*

One participant spoke about her adult foster child/ren coming back to the foster home to sleep on her couch;

*They slept on couches, when you asked me earlier how many people live in your home. If you asked me six months ago I would have said 13. Now we are down to eight and uh, because I am the mom [foster parent] ...*

Another foster parent parented her adult foster child through adult services and she was worried she would become homeless when she left her home;

*She was in a very bad situation right now, and I suggested she go back on her medicine, because when she's on medicine she's doing much better, she can control her behaviour. She doesn't argue as much as she does without it. So she was planning to go back to the doctor, she told me she made an appointment, and she's going back on her medicine because we thought [life without the medicine was very tough for her] like she's failing in everything the relationship, the job, even renting a littler place in basement is not working out for her because she can't control her behaviour. She can't control her anger issues, and she likes arguing and arguing without the medicine that there's no stopping her arguing with other individuals...my worry for her is that if she doesn't go back on her medicine and that relationship fails I'm worried that she'll be homeless.*

Five out of the fifteen interviews (33.0%) mentioned that their foster child had been and/or are currently incarcerated for a period of time. Three participants spoke of them being

detained through the justice system, while two respondents said their child had been admitted for medical purposes.

One respondent spoke of the age of the youth was when he first started getting involved with justice system;

*He is a child that, well an adult now that was diagnosed with FASD, and pretty soon after he was out of my care at the age of 14. That's when he decided to go off his medications and at that point he was in and out of [the] jail system to this date, and this is at least 13 years that have passed since.*

Another participant believed their foster child's incarceration was due to being introduced to drugs at a young age;

*Cause he was already introduced into drugs. He already knew how to get high from his pills. He then just got into bigger and harder stuff. And where he is now [named a high security prison].*

Even through all of their struggles, they often still try and reach out of support;

*I had two boys and one of them was kind of hard and I had to let him go when he was 15 because I couldn't control him. I told him when he would call, like he told me he was hurt when I let him go, well the reason I let you go was because I couldn't handle you, and he ended up in jail. He called me, I went to visit. I said to him, ok, you're here, I come to visit you, I will give you money but I told him next time you get into trouble don't call me cause I am not coming. That is exactly what he is doing. He did call me once [again] when he was in jail and I told him remember what I told you, if you get in trouble [again] I am not coming. He said ya, I remember.*

One of the participants mentioned that she believes that more training should be part of becoming a foster parent for children with FASD. If foster parents understand the needs of the children they may be better equipped to manage them;

*I think our kids in care in particular are being overmedicated, and I think a lot of it, I think part of the reason for that is you have caregivers that are, that may not have the training or a sufficient amount of training, to be able to deal with the behaviours that some of these kids have, may not have an understanding of where you know where these behaviours are coming from in terms, like when you have a kid that's um maybe reacting to its environment [gives an example about lighting].*

Whereas some foster parents took the initiative and received training, as one foster said,

*I kind of knew what to do to help him regulate, self-regulate... before all of that happened I went and did the course they have running, for people who work with children with fetal alcohol syndrome. I went and I did the course so I could have a clearer understanding and I worked close with the OTs [occupational therapist].*

Last of all, in order for children in care to be successful they need the support of family, this participant appreciated being able to share her success;

*Just being able to share that, is such a joy, it really is, where not very many foster parents can share the joy we have had building this [their] family. I think a lot of foster parents go through some stuff that is not right or fair, sometimes they have their struggles or they have kids that don't want to be there, we just have never had those kinds of problems. So that's the glory to God.*

When speaking about outcomes for children in care, participants mentioned the following themes; family; suicide; homelessness; incarceration; and that caregivers need more training.

## **Summary**

Numerous aspects of the school system contributed to the use of medications for First Nations children in care, with teachers playing a role in assessing a child's development and learning needs. Foster parents felt that the capacity of the teachers, the ability to acquire supports and the understanding of the school all impacted the necessity for medication. Respondents agreed that open communication between the home and the school were fundamental in ensuring the success of the child/ren at school.

Foster parents were equally divided about how they felt about the use of medications, some seeing positives results, others negative, with a few saw both. Forty percent of the respondents were very satisfied with the success the child/ren was having in school, feeling that the benefits to the child/ren learning needs and their ability to make better decisions outweighed any negative side effects.

However, many foster parents did mention that they saw negative side effects that the medication brought, such as lack of appetite, trouble sleeping, weight loss, moodiness or irritability. The correct medications and dosages were often a result of trial and errors before a proper fit was found. Furthermore, the mix of medications caused some children to be zoned out or zombie like, while three of the respondents had children with side effects so severe that they had to be taken to emergency.

In spite of the systems around them, or even what their foster parents believed, some children refused to take their medications. Nine of the respondents said that their child/ren at one time or another did not agree to take their medications. When they did take their medications, some did so out of obedience, with many quitting them completely when they became of age.

Most foster parents genuinely cared for their foster child, and did not want to medicate if there were other successful alternatives available. Many believed in other forms of interventions for teaching the child skills, such as daily repetition of structure and routine, making note that medications should not be the only source of intervention.

Forty percent of participants spoke of dependency on medications, which some believed then lead to street drugs. While sixty seven percent felt medications were overprescribed and we need to look at alternative interventions more than we are currently.

Overall, foster parents expressed the care and commitment that they had for their foster child/ren. Even after the child aged out of care, they stayed connected, they left the foster care system but they did not leave their foster family.

## **CHAPTER Four: Discussion**

### **Introduction**

First Nations children in the foster care system are more disadvantaged than children in the general population, and have higher rates of being born under the spectrum of FASD (Fuchs et al., 2005). Studies have confirmed that First Nations youth in care are overrepresented in the justice system (Shibler & Newton, 2010), have low educational outcomes (Mukherjee, Commers, Hollins & Curfs, 2013; Streissguth, 1997), and do not have healthy supports to connect with when they age out of care (Shibler & Newton, 2010) and making them more susceptible to become homeless (Chatterley-Gonzalez, 2010). They often face more challenges such as, multiple placements and group home care and often having no one to advocate for them long term or throughout the life span (Shibler & Newton, 2010). Secondary disabilities often result from these struggles (Davis, Desrocher & Moore, 2011).

Children in care are often disconnected from their family of origin which adds to the struggles they endure; and may also suffer a loss of their culture and identity (Fuchs et al., 2009). Within ecological systems theory, it is understood that for society to function at its best, individuals need to be supported culturally, socially and by institutions. When these elements do not mesh in positive manners entire systems can be dysfunctional (Siporin, 1980). On the other hand these children have unique experience and come with gifts and abilities that with proper interventions and opportunities can be contributing members to society. Ecological systems theory recognizes that all of these internal and external systems interact and impact the development of the child in negative or positive ways (Paquette & Ryan, 2001). While strengths perspective purports that each and every individual has unique strengths and abilities that need to be the focus, rather than just what they cannot do (Hammond & Zimmerman, 2010).

This discussion chapter will intertwine the findings from the interviews, with the analysis of the data from the demographic form, the broader picture of the field notes, the guidance of the theoretical perspectives, and the knowledge of the experts in the literature. The findings are the centre piece around which this discussion is built upon. The data from the demographic form will provide both further demographic characteristics of the foster parents as well as determining verification of their responses. The field notes provide some broader context to the lives and personalities of the respondents, while the theoretical perspectives attempts to provide a lens which with to examine a subject. Finally, prior literature helps provide evidence of thoughts and behaviours which had occurred before, and those that may be emerging trends.

This chapter is divided into five sections. The sections follow the same groups set out for the data in the findings chapter; (1) Process for determining the need for medication; (2) Schools as a main source of referral for medication; (3) Use of medications and other interventions; (4) Dependency created by the medication; and (5) Outcomes of children in care with FASD.

### **Process for Determining the Need for Medication**

Children in care face many losses, the loss of their family of origin, loss of stability and even loss of their culture (Douglas & Walsh, 2013; Fuchs et al., 2009). Many children in care experience trauma in their family of origin before they come into care. Once they enter into CFS the trauma of removal from their family home may become amplified. As some foster parents mentioned in the study once the child begins to feel safe, they often express themselves through behaviors as most often this is the only way they are able to express themselves. One foster parent mentioned that their trauma never really gets resolved in healthy ways of coping, which reiterates the cycle of family historical trauma (McKenzie & Morrissette, 2003). Because of the trauma that they have faced in the past, these children are often more vulnerable to experience

additional trauma through abuse or maltreatment in foster homes or in other relationships (Paley & O'Connor, 2011).

Another source of trauma that these children experience is multiple placements; this is even more common for children that have behavioural issues or disabilities. One respondent mentioned that her foster child had been in fourteen placements, as well as, an emergency shelter, before the age of four. Besharov (1994), Chatterly-Gonzalez (2010) and Jones (2003) all stated similar findings in research indicating that due to their challenging needs, these children often face escalating placements starting with foster homes, all the way to institutionalized care.

Being removed from their birth home and facing multiple placements are just a few of the different factors which create disruptions in healthy attachment within children in the foster care system (O'Malley & Storoz, 2003). Lack of healthy attachments can create behavioural problems as well as attachment disorders. In the findings respondents noticed the effects of attachment disorders in their foster children, as one mentioned that their child was very hard to comfort after suffering from multiple moves.

Attachment disorders can be difficult to manage in foster placements, but they can also occur within their homes of origin as well. It is important for foster parents to be aware of how to mitigate this secondary disability by creating long term stable homes, while in biological families it is essential that enough supports ( support worker, respite) are provided. Mothers' who are drinking tend to interact with their children less which has a negative impact on their developmental needs (O'Connor & Kasari, 2000). During one of the interviews, one of the foster parent's spoke of ways to make the child feel secure and develop healthier attachments. Her voice and demeanor had such calming presence which is a great asset when foster children who are anxious or detached (Field Notes, 2017). Aboriginal perspectives mention the need to

ensure that lives are balanced (Castellano, 2004). When children have attachment disorder their lives and emotions are imbalanced, the comfort and stability that foster parents provide attempts to bring with it some balance.

Trauma, grief and loss, multiple placements and attachment disorders are all examples of factors which often lead to development of secondary disabilities. Secondary disabilities mentioned by the foster parents were congruent to the literature, such as; intermittently explosive disorder, attention deficient disorder (ADD), mental illnesses, other associated disorders, low IQ and stealing. Davis, Desrocher and Moore (2011) point out that over 90% of people who have FASD, have ADHD as the most common co-occurring disorder. While three respondents spoke of the low intellectual abilities that they foster child had. One thing that stood out was that some of the foster parents did not realize how closely some of the traits of ADHD mirrored those of FASD, believing them to be completely unrelated disorders. This may be due to the fact that FASD is often misdiagnosed as ADHD (Coons, 2013).

Studies indicate that a character trait that children with FASD often struggle with is lying and stealing (Davis et al., 2011). A number of respondents indicated that they saw this behaviour in their foster children, mentioning that they would often take things that were not theirs, and also that they had a lack of understanding about others' personal space or property. Foster parents noted however, that even though they may have a number of difficulties, these children do exhibit strengths in other areas, as Millar et al. (2017) points out; although we all may have some deficits we are to be treated as unique persons. This is in line with the strengths perspective as it believes that in the inherent worth of the individual and that everyone is unique (Healy, 2014).



For children to come into care they must have faced adversity in their birth home, and once they are in care they often face additional issues. Those problems do not end once they leave the system as youth ageing out of agency care often get very little support. This can create problems as Sulimani-Aidan (2016) reinforce that youth often require more support after they age out. In the findings foster parents spoke of remaining connected to their foster children even after they aged out of their care. Forty percent of the respondents stated the youth did not leave there home after they aged out or at least remained connected. One responded spoke of her foster child remaining in care until age 21.

On occasion there are exceptions, where some children may acquire additional support from various systems. One respondent did mention her foster child getting external support when they aged out, being granted a disability allowance from Employment and Income Assistance (EIA) as they recognized FASD as a disability.

### **Schools as a Main Source of Referral for Medication**

When considering the findings, the themes that emerged significantly is the relationship the school had with assessing the need for medications as an intervention for the management of behaviors associated with FASD or his comorbid condition ADHD. Eighty seven percent of respondents stated that the school influenced the decision regarding the use of medication for First Nations children in the care of CFS agencies. This is not surprising considering that school is one of the first institutions of socialization for children, when they first step out of their family home. Schools being the primary initiator for children being placed on medication was a reoccurring theme for these foster parents as over half of them (53.3%) said that this occurred over the years with multiple children that they had fostered in their home.

The majority of foster parents indicated that it was the school that initiated the use of medications, but occasionally when a foster parent feels unsupported, they may turn to medications as an option to help them manage the behaviours of their foster child. In these cases they may approach their child's doctor to get medications prescribed. Coons (2013) agree that families of children with FASD need to have support from professional services.

### **School System**

Davis et al. (2011) mentions that drinking in the third trimester can cause damage to the numerous areas of the brain, which can result in multiple brain deficits (Mattson et al., 2016). These limitations can then manifest themselves through disruptive behaviours in the classroom or even learning deficiencies, which the teachers notice. These deviations from the behaviours of other children can alert the teacher and the school to there being something developmentally wrong with the child (Kalberg & Buckley, 2007). If the child has not been diagnosed with FASD prior to attending school, it is often at this point that their behaviours are questioned and they may be sent for medications to manage them in the classroom. Carpenter (2011) agrees that if there has not been a formal diagnosis of FASD in the pre-school years, the school then often becomes the first identifier. Popova, Lange, Burd, Nam and Rehm (2016) add that due to their behaviours, these children are often identified as difficult to manage in the classroom. They advocate for teachers having more training to be aware of what the disorder entails, to learn how to create adaptive classrooms and even to recognize what behaviours are potentially linked to FASD, to help identify those students for early interventions. Dybdahl and Ryan (2010) that sometimes the training that teachers are taking often do not meet the need of the teacher to equip them to successfully be prepared to create alternative to children with an FASD diagnoses.

As with every profession, teachers have different strengths and capacities. In the findings, participants noted that not all teachers have the knowledge of how to manage a child's behaviour in the classroom. Foster parents mentioned that they believe that the skills and abilities that teachers have can greatly influence whether or not they can manage children in the classroom, and ultimately if they will push to medicate the children in order to control their behaviours. They felt that some teachers who had greater capacity and were more willing to try innovative strategies to meet the learning needs of the children in the classroom. Some of those classroom models follow more of a strengths perspective, centering more on the abilities of the child and supporting them as opposed to focussing on maladaptive behaviours (Healy, 2014). Some teachers are willing to adapt their teaching styles to fit various learning types, ensuring that the materials were presented in different ways to fit various needs, while others did not. Foster parents felt that those teachers who were less willing to adapt their classrooms may blame their child for unruly behaviours, sometimes even separating them out as instigators. Furthermore the personality of the child appeared to also have an impact on how much the teachers were willing to accommodate, as one foster parent mentioned that her child was kind hearted and thus his teachers would advocate on his behalf. This finding is also true in Jones (2003) as it states that foster parents who enjoy their child's personality have better relationships.

Not only are teachers often the first to notice abnormal behaviours they can also have a lot of impact on the medication usage of children with FASD, as they interact with the children on a daily basis. As previously mentioned, teachers notice abnormal behaviours which could lead to a discussion about the need for medication. But their influence and observations do not end there. They will notice whether or not the medications are working, noting to foster parents when a child's behaviours have improved, the dosage does not seem to be having an effect, or if

they are having a negative impact. Carpenter (2011) agrees with this as he points out that teachers can be instrumental in observing behaviours and identifying need.

Twenty seven percent of respondents mention that there needs to be more support within the school system. This support can come in the form of teachers being more understanding about the disorder, educational assistants being part of the classroom, or by having an adapted learning environment that better suits the needs of these unique learners. Foster parents identified that education assistants, when they were available, were great assets for their children to have in the classroom. These interventions are in line with the ecological perspective as they provide the adaptive supports for children to succeed in school (Siporin, 1980). When their children received one to one support, they saw both the practical and academic skills improve. Having additional supports to take the burden off the classroom teachers may lead to a reduced need for medications to control behaviours.

This thought was voiced by a few participants, as their belief is that with more supports in the school, there would not be as an immediate need for medication. Many foster parents said that the child would be manageable at home without the medications but when they went the school, the teachers found their behaviour unmanageable. This could be due to the sheer number of children in the classroom and possibly the number of those children that may have the same or similar disorders. Additionally children are being asked in the class to follow social norms and models that may not be part of their structure at home. Further supports in the classroom could help them adapt to this more controlled environment, allowing them to also develop the social skills necessary when they reach higher levels of education or in their employment.

Supports in the school system, both inside and outside of the classroom, are all necessary to help in the management of behaviours. Numerous participants pointed out that agency social

workers were not a part of this process even though they are the legal guardian of the child.

Millar et al. (2017) discusses the need for players from multiple systems, from both the community and the school, to be involved in the planning process. Siporin (1980), using the lens of ecological system theory, agrees that the interventions which are used should not just focus on the individual but should take into account the systems surrounding them. These interventions should look to change systems to produce longer lasting outcomes. Multiple institutions and professionals were listed by participants in the findings as being involved in their child's care, such as; doctors, disability organizations, treatments centres and guidance clinics. Doctors are crucial in prescribing medications to children as well as assisting in monitoring the effects of those medications. Other organizations may or may not be part the medication process, but they all have their role in providing support to children with FASD and their families.

Chudley et al. (2005) purports the idea of there being more supports and early interventions in the classroom, while Buckley (2007) reminds that this is not an easy task as there is not a one size fits all as studies reveal that every child's learning needs are unique, even more so with children on the FASD spectrum. Ecological systems theory speaks about the goodness of fit between an individual and their environment, when there is a mismatch between the two, the situation is in conflict. This conflict must be resolved by the use of an appropriate intervention (Pardeck, 2015). This is what is occurring with the classroom setting for children with FASD, their learning style and that which is being used in some classrooms are not congruent with each other, thus causing the child to act out in manners which can be perceived as deviant. This theory outlines that the interaction between the individual and the environment is ever changing, if the environment changes, the individual reaction to it changes as well (Pardeck,

2015). Thus if the classrooms become more adaptive, the behaviours and learning outcomes of the children will adapt to that change.

Another barrier to getting more support is the need for additional funding, which may be difficult to acquire due to deadlines, budget constraints and regulations. School budgets may be limited, however, resources are extremely important to help educators get the proper training that they need, as well as getting the additional supports that the students require to be successful. Both of these aspects will create better long term outcomes for society. When teachers are educated about the disorder they can recognize traits of FASD, realize that it is not the child being willfully defiant of their authority and create more adaptive teaching methods in the classroom. For children, the additional resources, such as an education assistant or a computer that they can use in the classroom, will take some of the burden off of the already taxed classroom systems and give them the help that they need to become independent and productive members of society. Popova, Lange, Burd, Nam and Rehm (2016) agree that more supports aid in creating positive learning outcomes, and may diminish the need to choose medications too quickly as there are no other alternatives. In order to build capacity for students we need to start with educators (Popova et al. 2016). Finally, foster parents indicated that they saw part of their role was to be an advocate in getting additional resources and funding for their children to thrive in school. Duquette et al. (2007) agrees that advocacy is large role that foster parents can play in their foster child's education. Using anti-oppressive practices, allows for the needs of a child to be addressed while attempting to break down the barriers that have contributed to the dysfunction in their lives (Brown, 2012).

Foster parents understand that open communication between the child's home and school is an absolute necessity. Dybdahl and Ryan (2010) agree as when teachers took the time to

Speak with foster parents of children with FASD it resulted in positive outcomes. After they spoke to them, the teachers began to view the foster parents as more of an authority on the child's behaviour and disorder as well. Millar et al. (2017) says listening to foster parents regarding their child's abilities adds to success, utilizing innovated planning helps to diminish secondary disabilities. Unfortunately these regular communications may not happen all the time, as the authors point out that it takes time that the teachers do not have.

We should always be finding ways for students to learn in the classroom setting. Sometimes this may include the use of medications to help them focus and to manage their behaviours, but medications will not work on their own. We need to be constantly thinking about ways to improve, and plan for success in order to have better outcomes with children with FASD.

### **Use of Medications and Other Interventions**

The findings showed a mix of perspectives about using medications as an intervention for children with FASD. Some foster parents believed that it had positive effects on their child's life while others spoke about the negative effects. The use of medications as an alternative does have some positive advantages along with negative results, as the findings reveal it can help the child manage their behaviors better in the school setting. Parents and children need to be given the choice which can impact long term outcomes for learning but should not be the only interventions or the first option to go to, as there are a variety of alternatives that need to coincide along with medications.

The findings indicated that some foster parents saw positive outcomes when the medications were used as an intervention to help children in the school environment. Foster parents stated it helped the children focus, maintain control; allowing for better socialization and

learning. Ozsarfati and Koren (2015) say that the benefits to medication need to be considered as these positive results may outweigh the side effects.

Respondents stated that the decision to utilize medications as an intervention was not an easy decision to make, as it was emotionally difficult due to fear of harm. What did alleviate stress to this decision was the support from the school and professional in the systems that foster parents received. When foster parents notice some positive outcomes they were at ease and believe they were making the right decision as some parents mentioned it is not for every child with FASD. But not to have the choice to utilize medication may be placing children at a far greater disadvantage.

Eighty percent of respondents noticed that their foster child suffered from at least one side effect from the use of medication. The most common effects were; loss of appetite, weight loss, mood swings, irritability, and trouble sleeping. Hanlon-Dearman, Green, Andrew, LeBlanc and Cook (2015) listed all of these as common side effects to stimulant medications. However, these listed side effects have been acquired from studies on adults as there are very few studies conducted on the effects of these medications on children (Clavenna & Bonati, 2014; Ozsarfati & Koren, 2015), with only nominal research on the long term effects (Clavenna & Bonati, 2014). Although the medications may have some of the same side effects on children as they do on adults, the question is still what additional effects they may have on their developing minds and growing bodies. As there is limited research, we cannot know what the long term effects of taking these medications will be.

Even in the short term medications can have unexpected effects on the children who take them, and those side effects can come as a result of one medication or from the interaction of taking multiple medications. Twenty percent of respondents reported negative interactions



between the medications being administered and the body chemistry of their foster child. As a result those children needed to be immediately taken off all medications to stabilize their condition and to investigate the cause of the adverse reaction. This is contrary to the beliefs and values of Aboriginal perspectives as the use of these medications throws off the chemical balance of the child, thus causing discord in their life (Verniest, 2006). Although there is limited literature that mentions the possibility of interactive effects of medications taken by children with FASD (Timimi & Taylor, 2004), Burd and Christensen (2009) speak out about the need for more clinical trials to determine what effects even solitary medications are having on these children.

One side effect that is not mentioned in the literature is that the child can be ‘zoned out’ when taking the medications. Forty percent of respondents reported their foster child experienced a ‘zombie like demeanor’ when taking the prescribed medications. A participant’s described the experience as though the medications were taking away their child’s spirit. This effect may be caused by overmedication or the body chemistry and the medication did not match. Aboriginal perspectives look not only at an individual’s physical being, but is also considerate of the spiritual nature of the child, which can also be thrown out of balance by the side effects of medications (Castellano, 2004).

The findings state that foster parents bear a burden in their role of administering and tracking medications for their foster child. This is especially true when children refuse, hide or use their medications to get high. Hanlon-Dearman, Green, Andrew, LeBlanc and Cook (2015) caution against misuse or abuse, and those who are in charge of this process need to be aware and highly in tuned. They further point out the necessity of finding alternative practices rather than relying solely stimulant medication.

Sixty percent of respondents used alternatives to medications or alongside of medications, some of which are highlighted in the findings. A number of foster parents mentioned that structure, routine and repetition were key learning techniques for children with FASD. This is also stated in the literature as Paley and O'Connor (2009) discuss that predictable schedules, which are implemented consistently, can assist in alleviating learning challenges. In general, even children without a cognitive disorder need to have structure and routine in their lives to help them learn the skills that they need to be successful at work and in their adult lives. This need is amplified in children with FASD as some of the challenges of their disability include having a poor memory; poor retention of instructions; difficulties listening and processing auditory material; and having a short attention span (Carpenter, 2011). By practicing newly acquired skills, children with FASD can move the learning into long term memory which should help solidify it into their lives. Additionally, Kalberg & Buckley (2007) mention another strategy for development; making the child aware of their thought processes which should help them understand and store new information correctly.

The U.S. Department of Health and Human Services (2007) agree children with FASD do well in a structured environment. Structure and routine play a role, as well as making sure that the amount of triggers are reduced (Kalberg & Buckley, 2007). Participants indicated that reducing the stress of an environment by making it clutter free, eliminating unnecessary distractions, ensuring that the noise level is calm and serene lighting helped to keep their children on task and provided better opportunities to learn. Within the field notes this is a common theme. In the homes that were visited for the interviews, the foster parents kept the spaces organized and free of clutter.

External environmental influences are important factors, but so are those that are closer to the child themselves. Foster parents indicated that utilizing headphones to drown out distracting noises, deep breathing techniques, changing activities often and even making sure that the child was dressed in clothing that did not irritate them were all techniques used to help them self-regulate.

External supports can also be beneficial as the findings reveal the need for children in care to speak with someone who is a neutral party. Not their social worker nor their foster parent, but a trusted teacher, friend or safe adult who they can voice all the things that are common struggles that foster children go through. Every child needs a mentor, not just children with FASD as it allows for the child to speak freely about what is going well in their life as well as what problems they may be having.

Burd et al. (2003) speaks to the internal and external factors of the development of FASD, and speaks to the role that nutrient plays in prenatal care; this may have a greater influence and cannot be overlooked as nutrition has a major role in healthy development. A recommendation would be better nutrition as the findings indicate that the potential for good nutrition to mitigate with self-regulation is promising. One parent even mentioned that using chores to keep them busy while teaching them routine and life skills was an important part of their development. Carpenter (2011) advocates for the use of many intersecting strategies, believing that multiple learning styles help children to learn.

Kalberg and Buckley (2007) speak of the need to treat the environment as the external brain of a child with FASD. Remembering that factors within, and changes to that environment, can have major impacts on a child. The environment should help fill in some of the gaps that the children cannot do for themselves, helping them set boundaries and better understand what is

expected of them. Visual aids can be a help in their learning environment, as McInerney (2001) points to using visual cues as reinforcement for auditory instructions to create a more structured and secure environment for children. An example in this study was, one foster parent mentioned that she used a visual chart to keep her child on track with teeth brushing and hand washing.

In the findings, parental patience was an important piece of a child's environment. As one foster parent put it, children with FASD may take longer to understand, and to figure out how to accomplish tasks. They need to be taught to not be discouraged and to keep working away, and parents need to be adaptable as children with FASD will make mistakes, and they learn differently so we need to adjust to their learning styles and abilities, and not them to ours. This follows an anti-oppressive approach as we are focusing on what is best from the children and not making them conform into the systems that are in place (Potts & Brown, 2005).

Discipline was also mentioned as an important part of interventions for children. One respondent spoke of the lack of discipline that she sees overall with young parents and managing their children's behaviours, not just those children with FASD. Discipline fits with the idea that children with FASD need structure and routine in their lives; it is letting them know where the boundaries lie and correcting them when they push beyond them. During one of the interviews, the interviewer observed the interviewer interacting with her spouse and biological children. She was very skilled at disciplining her children, who in turn had very clear ideas about her expectation (Field Notes, 2017).

The findings reveal the need for skill building in conjunction with medications, as one responded states that medications are good and meant for a short period of time and need to be used for the purpose of adding additional skills building (self-regulation and stabilization) and

not meant for long term use without any other interventions. As it is unknown the long term ramifications of a young child's developing needs when using medications long term.

Two thirds of respondents (66.0%) said that they believed that medications were over prescribed and they feared that they were over medicating their foster child. Medications often did not go through the hands of the legal guardian, in the case of kids in care, which would be the child welfare agency. A number of foster parents felt that medications were pushed onto them by the school and that their voices were not fully heard by the school system. It is surprising that the schools would not take more notice of what these foster parents said as they came across as educated, confident and knowledgeable during the interviews (Field Notes, 2017). One foster parent mentioned that she had experienced this with all of the children that she had fostered, feeling that the school and doctors choose to medicate especially First Nations children before they try alternative interventions. Another participant spoke of the process that one of her foster children went through, that the school and teachers decided that as soon as the child was in care [most likely as a permanent ward] that they should be placed on medications. Some foster parents felt that they were seen as having less authority to advocate against the systems of power, and the move to medications, than the biological families of the children would have. Others felt that after years of fostering, when they had more experience they were able to advocate more on their foster child's behalf against the use of medications, or at least against only medications being used without accompanying interventions. Ecological systems theory agrees that interventions require a multi-disciplinary approach to have the best treatment plan possible (Siporin, 1980).

Finally, the respondents felt that sometimes kids are kids, they are not just a label or only a diagnosis. Children with FASD may need more supports and care in place but they will still

have the same types of day to day struggles as your typically developing child will encounter. Foster parents believed that some of the behaviours which children are being medicated for are aspects of childhood that all youth go through, such as young children being hyper or teenagers having difficulties due to changing hormones. They felt that the children would just grow out of some of these behaviours, and that at times medications were chosen too quickly to regulate. O'Malley and Storoz (2003) confirms that studies do indicate there is a strong potential the children may outgrow at least some behaviours, as they found that animals who had alcohol exposure before birth showed decreases in certain behaviours as they grew.

### **Dependency Created by the Medication**

Forty percent of respondents spoke of the dependency on medications that are created when their foster child had been taking them for an extended length of time. Foster parents mentioned that their children would ask for the medications in order to regulate their moods, or for going to school, sometimes feeling anxious when they do not have them. One participant spoke of her foster child being medicated since the age of five, and is now an adult, being now so dependent on the medications that when they aged out of care and the system no longer paid for the drugs that they would steal them from younger children in the household. This again speaks to the need of further research needed to explore the long term effects of medication on the developing child and what dependencies that can be created. Hanlon-Dearman, Green, Andrew, LeBlanc and Cook (2015) indicate that there is a lack of long term studies in that respect. Medications cannot only lead to dependency on the drugs themselves, but also on the systems that supply them as Timimi and Taylor (2004) speak out against the dependency that is created on the medical system. This dependency can create major problems when the foster child becomes a legal adult and is no longer under the care of CFS. Respondents expressed their

concerns about who would cover the costs of those medications, fearing that their children would not be able to pay for them, as well as what the consequences would be if they had to stop taking the medications suddenly.

Foster parents also felt that they were not given enough information about the medications and potential side effects. This is consistent with the literature; however, some of those side effects are often not even known (Timimi & Taylor, 2004), making the information difficult to provide in the first place. Guidance about how medications should be administered can also be missing; leaving it up to the foster families to try and figure out on their own.

Using medications can have extreme effects on the bodies of children, leading to a few of them requiring to be admitted into a treatment facility to undergo a medical stripping of all the medications they were using. This can occur due to allergic reactions to one or more of the medications, or due to a negative interaction effect that using multiple medications had. In both cases the child was approximately 12 years of age and needed to have all the medications cleared out of their system to avoid causing damage. Timimi and Taylor (2004) mention that the drugs that these children are on are often highly addictive, and have brain-disabling side effects in animal trials. Hanlon-Dearman et al., (2015) also indicate that families need to make sure that the medications do not get used misused or abused.

Hanlon-Dearman, et al.,(2015) speak of the misuse or abuse of medications, and how this may be a gateway to harder street drugs. Some foster parents blamed the overuse of prescribed medications for their foster children getting into and becoming dependent on street drugs, mentioning that they believe that it made it easier for them to try different substances. Twenty percent of respondents clearly stated that their foster children were now dependent on illicit

drugs, sometimes drinking cough syrup or chewing Gravol to get high. Others smoke marijuana to regulate themselves, choosing to avoid the side effects of their prescribed medications.

Over half of the foster parents (60.0%) said that their foster child had refused to take their medication at least once when they attempted to administer them. There were numerous reasons for the refusal including; the child could not swallow them, the child was suffering from side effects, and the youth was of age to make the decision to take them or not.

Five of the foster parents (33.3%) only gave their foster children medications for school, stating that they could manage their behaviours on the weekends and holidays. They said that the medications affected the way that their children ate, slept and even felt, and that they wanted to give them a break from them whenever they could. Some participants felt that medications were more of a school thing, something that the teachers needed to manage their classrooms, and that they were not necessary to manage the behaviours at home.

Children who take these medications often feel like they are forced to do so, with over half of them stating that they would stop taking them if they could (Barnett et al., 2016). In the findings, seven out the fifteen respondents (46.7%) indicated that once the youth was of age, they decided they were not going to take them. Even though some foster parents believed their foster child would manage life better if they continued taking their medications.

In the interviews, foster parents indicated most of the children in their care were placed on medications between the ages of five and eight. Although some children were on medications by the age of four, while others as late as fifteen. These medications are often potent stimulants (eg. Concerta, Biphentin, Dexedrine) or anti-psychotics (eg. Risperidone), which are not meant to be taken at such a young age (Concerta, 2016).



One respondent noted that the common age for refusal was eight or nine years, while youth just discontinued taking the medication during their teen years (between fourteen and fifteen years of age). Children were not the only ones that would refuse to follow the prescribed medications as there were some foster parents that said that they just refused to administer them at some point.

These are important findings as it brings to light an important dilemma. Although children are not considered to be capable decision makers until they reach the age of majority, many of them start to form their own opinions about matters that affect their lives earlier than that. The age of majority in this province is 18, although some foster children remain in the system until the age of 21. However, the Manitoba *Child and Family Services Act (1990)* states that any court can hear the wishes of children over the age of twelve, and for those under that age, their views will be considered if they are deemed to be capable of making sound decisions, which are in their best interests. The question then needs to be asked “At what age do we start listening to the voices of children when they tell us what effects the medications are having on them?”

### **Outcomes of Children in care with FASD**

Children with FASD have both higher rates of suicidal thoughts (O’Malley & Storoz, 2003), as well as suicide completions, than their non-affected peers (Shibler & Newton, 2010). The literature also notes that both biological and environmental factors can impact mental health and thus depressive or suicidal behaviours. Being removed from their birth home, multiple moves, death of a parent and ongoing placement in CFS are some of the factors listed as having an impact (Hellemans et al., 2010; Streissguth & O’Malley, 2000). A few participants mentioned that suicide was a problem for their foster children stating that they would need to

keep a close eye on the medications which they took to ensure that none were missing or that they could overdose. One respondent mentioned that one of her foster children attempted suicide because her birth mother had committed suicide, saying that her depression would just take over.

Problems with mental health and emotional stability can lead to further difficulties for foster children when they leave care. Chatterley-Gonzalez (2010) found that youth in foster care who are aging out of the child welfare system are susceptible to becoming homeless, having nowhere to go after their supports have been removed. Foster parents in this study expressed their concerns about their foster children becoming homeless, indicating that once they leave care and are no longer their responsibility they may stop taking their medications, and without the supports needed may not be able to maintain a stable lifestyle.

While some foster children become homeless after they leave the foster care system, others behaviours put them into institutions. Popova et al., (2011) found that were more likely to have contact with the law, and also be incarcerated or institutionalized at some time in their lives. A third of the participants mentioned that their foster children had been or are currently incarcerated; three through the justice system and two in medical facilities. One respondent mentioned that she believed that the use of prescribed FASD medications created the dependency on harder drugs, which ultimately led to him being imprisoned. Hanlon-Dearman et al.,(2015) also mentioned that families need to be aware of the potential problems with the medications that children with FASD are using, making sure that they do not move from prescribed stimulants to street drugs.

Brenna et al.,(2017) point out that it is crucial to notice the strengths of the individual rather than solely the deficits. This fits exactly with the strengths perspective, as they too believe that an individual should be recognized for what they can do, rather than just what they cannot

(Hammond & Zimmerman, 2010). They further stated that if we, as a society, are going to move towards being an inclusive society, we need to be focusing on strengths as it is imperative in addressing the needs of learners with an FASD diagnosis in the classroom, as well as in the community. Mukherjee, Commers, Hollins and Curfs (2013) add that often times children with FASD struggle through school because we focus too much on what they cannot do, and not what their strengths are. This may be due to society not understanding, or not being willing to accommodate, the needs of this group. Ecological systems theory centres itself around the idea that a deviant individual is not always disturbed, that they may be reacting in abnormal ways due to a breakdown between their capabilities and what society expects of them (Pardeck, 2015).

A number of foster parents mentioned that they believe that it would be beneficial for more training about FASD what potential challenges and behaviours come with the disorder, to be provided to care givers. Some participants had taken the initiative and had already attended specialized programming. Knowledge of FASD is an important concept for foster parents to understand, however culture is another aspect of these children's' lives. Of interest, is that within this study eight of the fifteen respondents identified with First Nations or Métis descent.

Eighty percent of respondents indicated that they continued to stay connected to the children they had fostered even when they had aged out of the CFS system. They spoke of dual reasons for contact; the foster child's continued need for a family, as well as their own needs to remain close to the children. Many of the foster parents in this study were extremely committed to their foster children as their words, emotions and demeanor expressed this, during the interviews (Field Notes, 2017). Some foster parents are so committed to their foster children that they adopted them, or have retained them within adult services (Field Notes, 2017). This need for connection was especially evident during holidays or special occasions. When children leave

their home of origin, it is often because it is in crisis and as a result they may spend the majority of their childhood in foster care. When they age out of care they often do not have a family to go back to, and if they do, it may provide them with limited support. It is for these many reasons why it is so important for them to be able to retain a connection to their foster families even when they are adults. Jones (2003) reiterates the idea that children need lifelong families especially when they go through significant transitions, such as ageing out of care.

The foster parents who were interviewed had a perceived investment for the foster children that they had in their home. During the interview one of the respondents became emotional about the struggles that she had when advocating for her foster children (Field Notes, 2017). She said; "...it has been a long struggle it has been a fight I have fought with the school. I fought with the doctors about trying to help these children". They are passionate about improving the lives of the children that are in their care.

The foster parents in this study may be atypical of the average foster home. Forty percent of the foster parents ran what is considered to be specialized treatment homes, and thus offered substantial amounts of support. Ten of the fifteen participants worked solely as full time foster parents within the home. The average number of years of experience is 17 years. These are foster parents who have fostered for a long time, a large number of children (11.2 children with FASD/foster parent on average) and have a lot of experience. There are many more children that exit the foster care system that are not as fortunate as those that have been a part of these families. As Chatterley-Gonzalez (2010) points out that many children in care with FASD have a greater potential to be homeless once they have left the system.

Coons (2013) states that when families create protective bonds it can lead to positive coping strategies. In amplifying the voice of one foster parent, "*So, family is family no matter*

*what it looks like or how we got together, we are a family*". We all need family, children especially so. Whether that family is the one that they originated from, or the one that they developed while being raised in the foster care system, they need healthy supports that they can turn to all of their life.

## **Summary**

Through intertwining the findings with the theories, field notes, responses to the demographic form and information from the literature review, a broader basis of knowledge has been created. Using those various sources, the discussion examines in depth the theme groupings which emerged from analysis of the findings. By linking together the subsections of each of the five theme groups, common threads were evident. The discussion began looking at the common struggles that children in care face; followed by schools as a main source of referral for medication; use of medications and other interventions; Dependency created by the medication; and concludes with outcomes of children in care with FASD.

What has been evident in this study is the influence that the school system has of both the education needs of its students as well as the push for the medication of children with FASD. As shown through the findings in this study, is through this system of power that initiates the use of medication as an intervention, which may in turn repeat a cycle of dependency on systems. Alternative interventions have been used in combination or instead of medications, although due to budget constraints they may not be used in schools as much as would be desired. The findings conclude with the idea that these foster children need the support of the family throughout the life cycle, as youth became adults and are no longer supported by the foster care system.

## **CHAPTER Five: Recommendations**

Key practice recommendations were outlined in the following areas; systems of power, adaptive classrooms, the FASD continuum, tracking medication usage and supporting foster homes. Following this three research recommendation are set out to guide future studies.

### **Practice Recommendations**

#### **Systems of Power**

Ecological systems theory speaks of systems of power and how they influence and interact with individuals in society. Schools comprise a very powerful system that has a great influence on the utilization of medications for First Nations children in care, with many foster parents expressing they may be too quick to medicate, instead of looking for alternative interventions. Numerous foster parents mentioned that the schools would push for the use of medications, even when they would be hesitant to agree, for behaviours that many foster parents felt they could manage at home. They also felt that the schools did not see them as an authority on their foster child. This is perhaps due to the fact that they are not the legal guardian of the child, as that is the role of the child welfare agency. However, this is problematic as although the child welfare agency is the guardian they almost never consulted in the medication process for the children in their care. Child welfare agencies also are a large system of power in the lives of children in care, and because they are invisible in this process, it leaves a gap in who has the authority to make the decisions about whether or not the child will be placed on medications. The decision about medications needs to be made by someone close to the child that has an investment in their long term care and success. Foster parents can be a source of advocacy for these children if they were given the authority, as well as the accountability, to do so. Alternatively, child welfare agencies could also have more of a hand in the process; before medications are prescribed and

used rather than after the decision has been made. Systems of power should be balanced, taking into account what is best for the child, instead of solely what is best of the system.

### ***Recommendation #1***

Prescribed medications to manage FASD and ADHD should be required to go through the hands of the child welfare agency before they are given to the foster child. The agency needs to be the authority on the process. Foster parents, placements and social works may change through the life of the child, especially so when there are unmanageable behaviours, but the overall child welfare authority should remain the same. The child welfare agency needs to create the stability in authority over their medication needs.

### ***Recommendation #2***

The school system needs to be held accountable for their push to medicate children in care with FASD. The need for medication must be warranted, and what is best for the child needs to be taken into account. Medication cannot happen solely for the purpose of managing their behaviours, there must be benefits for the child.

### **Adaptive Classrooms**

Although schools in Winnipeg are the global leader in providing support in education and intervention for children with FASD (Miller et al., 2017), there is still a lack of knowledge in how to manage the variants in need associated with the disorder. Some behaviours or needs associated with the disorder may be common to the majority of children with the disorder, but there are many more that are unique to each individual. Although not all classrooms need to be inclusive, there should be some that have adaptive systems to fit the learning styles of children who may not fit into the traditional classroom molds. This could have the potential added

benefits of working for children who are not FASD or ADHD, but perhaps have a learning disability or other academic struggles.

The dynamics of education are ever changing, and the idea that all students will follow the path of academics and enter into universities needs to be more realistic. Students on a whole are looking more to schooling systems which, in at least some part, provide adaptive learning for entering into the workforce. Children in care who have FASD often have low educational outcomes, resulting in secondary disabilities and lack of employment when they leave school. By creating educational environments that are designed to help them succeed, these negative outcomes may be mitigated. In using a strengths perspective to focus on the capacities of the children, schools can create learning environments that facilitate higher educational and employment outcomes for children with FASD.

### ***Recommendation #3***

Schools need to tailor some of their classes to fit the needs of this population. The focus needs to be on practical learning outcomes which can lead to employment. Students need to be taught life skills in order to successfully manage their lives and jobs when they leave high school and the care system.

### **The FASD Continuum**

Children with FASD fall onto a continuum, varying in degrees of disability from low to moderate to severe. This can cause problems in terms of acquiring supports, as children who are low on the spectrum may not need supports and may function on a relatively average scale the majority of the time, with minor deficits in some areas. Children with severe FASD have obvious needs for support, and even after aging out of care may be able to access adult services which would continue their support for as long as they need it. It is those children that fall into



the moderate level who may face the largest challenges. Children with moderate FASD are not as high functioning as those on the low end of the spectrum, but they have higher educational and social expectations on them than children who are at the high end of the spectrum. Also, they may not receive the supports that they need as their needs are not as evident as those at either end of the spectrum. This may be due to there being a wider range between cognitive abilities and executive functioning than other groups. It is that disconnect between what they understand and how they make decisions which can lead to secondary disabilities. Children with moderate FASD may have higher rates of homelessness and unemployment than those that fall at the bottom and the top of the spectrum.

#### ***Recommendation #4***

Children in the middle of the spectrum need supports tailored to their unique needs. Providing mentors for these children would allow for one on one skill development which could focus on the areas where they need assistance. For example, children with FASD often find it difficult to socialize and mentors can help fill this gap.

#### **Tracking Medication Usage**

The process of administering and tracking the use of medications should not be taken lightly. Foster parents have a tremendous role to play in this process. They are essentially the guardians of these medications, needing to ensure that their foster children take the medications, while not taking too many. They are also asked to assess the effects which the medications have on the child, and whether they are a benefit or a hindrance. Considering that they are highly potent stimulants or anti-psychotics they require lots of observation is essential as trials are necessary in finding right fit of medications. Furthermore, due to the nature of these medications there is the potential that children could become dependent on them, or that they could be a

gateway to street drugs. This can be asking a lot from foster parents, who often feel like they have nowhere to turn to in order to get support or advice on using medications.

***Recommendation #5***

Child and Family service agency should be involved in this process by tracking medications given, as workers are often overloaded with case management and may not have the time to be involved in the process. Social workers who work in child welfare should have a least basic training what types of medications are prescribed for FASD and its related disorders, so that they can help foster parents understand if they have questions. This is a larger responsibility for foster parents; they should not feel alone in it.

**Supporting the Foster Homes**

In the literature it is noted that the commitment of the foster parents and the support that a child receives in the home is crucial in mitigating secondary disabilities. In knowing that foster parents have a great influence on the life of a child, we cannot underestimate the need to provide support to foster parents who are fostering children with high needs. More supportive home environments may provide preventative measures which have the potential to have positive long term effects.

***Recommendation #6***

As foster parents are such a valuable resource in the life of a foster child, it is vastly important that they are given enough support to meet the challenging needs in parenting a child with a disability. There needs to be adequate respite support in these homes, allowing time for both the foster parents and foster children to have time away from each other.

## **Recommendations for Future Research**

### ***Research Recommendation #1***

One of the questions that came up while conducting this study was; Are there differences in the demographic profile of the children who get recommended to take medications? This could include analysis of whether children who have behavioural problems, but do not have FASD are pushed into medications as quickly as those who do have FASD. Research needs to be completed to determine if children with specific ethnicity (i.e. those of Aboriginal ancestry) are placed on medication more often and earlier than children of different ethnicities

### ***Research Recommendation #2***

This recommendation has been pointed out by numerous studies before, but it warrants being mentioned again, especially since it has not been fulfilled. There needs to be research trials conducted in order to determine what effects these medications are having on children, especially in the long term. Children are placed on these medications, some at a very young age, with limited knowledge of what effects they are having on the body, mind and spirit of these children.

### ***Research Recommendation #3***

There does not appear to be an easy answer to the question of “who is defending these children?” When considering all the systems and people involved in the life of a child in foster care, who has the greatest capacity to be the defender of the child? Should it fall squarely on the shoulders of Children’s Advocate, or is there another institutional body that would be better suited for that role? This requires further thought and development. But it is likely that not one system or individual will be the best fit for all cases. It may be in fact a combination of systems

or individuals that may be necessary to fit that need. Further studies are necessary to delve further into how these multiple systems interact and what approaches can be used to better help the children.

## CONCLUSION

Aboriginal perspectives believe in the value and innate worth of everyone, regardless of age, class, or gender. These children are being devalued, and the parents' voices are not being heard, children may be thought of as too young or too damaged to know what is best for them. And while it is true that children need guidance and mentoring, they still understand how the medications are making them feel. The child welfare act allows for children to speak in court at the age of 12, and have their thoughts taken in account younger than that. However what the act states and what is occurring in reality are often two different things. Children are said to have choices, but in actuality that is not always true.

One of the most important messages in the findings is around the idea of providing choices to children when prescribing medications. Children need to be heard. But by whom is part of the question. The obvious choice is their foster parents, but they are not actually their guardians and their level of investment in that child can vary greatly. The same can be said of the child welfare agency, who is the legal guardian of these children. Workers come and go, have many families on their case load, and rely on the foster parents to do all of the heavy lifting on providing support to these children. Most schools and doctors have even less investment in these children. Not wanting to see harm come to them, but also not managing them on a daily basis.

Every child needs a champion. Someone that they can rely on, someone they can count on. As a society we think that this person is their parent. But we need to realise that sometimes it is, and sometimes it's not. This is true for all children, in foster care, or not. However, for children in foster care their parents may have never been in the picture, or may still not be healthy enough to take on that role. So who then does it fall to? This is not an easy answer. The

obvious choice would be the foster parents, but as mentioned in the discussion, there are varying degrees of foster homes. Some are more committed than others; some have more capacity; some are more educated; some are more supported. All of these factors have an impact on the stability of the children in their care, and ultimately what happens when medication usage is suggested.

So then does it fall to the agency? How can an agency be the sole decision maker about a child using medications when they may only see them once a month for an hour of time. Can that time, and collected information (assessments, teacher's reports), provide enough insight to the worker to make that call. Teachers have to manage multiple children on a daily basis, and have different level of tolerance and capacity themselves. Deviant behaviours can have a large impact on the classroom and the teaching which can occur. Can teachers adapt to all of the different needs of all of the unique learners in their class. It is doubtful that they can be the advocate for all the children which they teach.

Currently, large systems of power make those decisions. Sometimes they may be acting in the best interest of the child, but by in large it would appear that they are acting in the best interests of the system. That is not to say that medications do not have their place, and foster parents have seen benefits to their usage. Foster parents were torn in this research study between the side effects that they witnessed their foster child experiencing, and the suppression of deviant behaviours especially in the classroom. But the fact is that we are still placing children on highly addictive medications that have no long term effects studies, without listening to how they feel. Which some respondents believed it could create dependency. And perhaps without looking at non-medical alternative interventions before we medicate them.

The question then begs to be asked, even if the foster parents and the child do not want to use medications, is that even their choice? When does it come down to listening to the voice of the child? Children and youth have voices too, and it is time they are heard.

**APPENDICIES**

Appendix A: Request Letter to Agencies

Appendix B: Recruitment Poster

Appendix C: Invitation Letter to Participate in the Study

Appendix D: Summary Letter for Advertisement Posting

Appendix E: Telephone Script

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Appendix H: Interview Questions – Foster Parents

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Appendix J: Confidentiality Pledge



**APPENDIX A: Request Letter to Agencies**

(to be printed on University of Manitoba, Faculty of Social Work letterhead)

[Enter date]

[Enter agency Name]

[Enter agency Address]

[Enter Title of Director]

I am an Anishinabe woman, and have been both a foster parent and an early childhood educator for over 20 years. For the past nine years I have worked in Child and Family Services, and have supervised for over a year and a half. In 2008, I graduated with a Bachelor of Social Work (University of Manitoba), and am currently in the thesis stage of a Master's of Social Work.

I am in the process of completing my thesis proposal and I am seeking your approval to conduct the study. I am requesting assistance from your agency to help recruit foster parents of children that fit these study criteria permission to be a part of a research project for completion of my Master's thesis.

The topic that I am researching is called; the lived experience of foster parents in placing First Nations children in care on medication for the management of behaviors associated with Fetal Alcohol Spectrum Disorder (FASD) or its comorbid conditions; such as attention deficit hyperactivity disorder (ADHD). The purpose is to hear the stories of foster parents, to gain insight from their lived experiences.

First Nations children are over represented in Child and Family Services (CFS) in Manitoba. Children come to the attention of CFS agencies for many different reasons, however there are often some common factors, such as; family historical trauma, parental abuse and alcohol or drug addictions. Those high rates of alcohol addiction have led to children being born into the umbrella term FASD, often leading to life-long challenges.

In response, many Aboriginal children, in the care of child welfare agencies, are being placed on medications for behaviors attributed to FASD. This study will examine the processes when First Nations children are placed on medications for FASD or its related conditions, using exploratory qualitative semi-structured interviews with foster parents of First Nations children who have those conditions.

The goal is to conduct approximately 12 to 20 interviews with the foster parents whose First Nations foster children are on medication. In addition, participants will be asked to fill out a questionnaire providing some basic demographic information, as well as, the principal investigator will be taking field notes during the interview process. Their responses will be kept in confidence and will not be identified to anyone other than the researchers. Any identifying comments or characteristics will be removed from any documents accessible to the public (e.g. the final thesis report), in order to maintain this confidentiality.

The only individuals who will have access to the raw questionnaire, field notes and interview data will be myself (Simone Richard, Principal Investigator); my research assistant (to aid in transcriptions and data entry), who will sign an oath of confidentiality; and my U of M faculty advisor (Dr. Cathy Rocke). This research project has been approved by the University of Manitoba Psychology/Sociology Ethics Board.

By giving a voice to foster parents we will be able to gauge whether we are on track by using medication as an intervention for FASD. This knowledge will help with future planning purposes, as well as informing policy.

I thank you for your consideration in this matter. If you have any questions about the research project, feel free to contact me at [REDACTED] OR [REDACTED] OR call [REDACTED].

Respectfully,

Simone Richard, BSW, MSW (Candidate)

**APPENDIX B: Recruitment Poster**  
(to be printed on University of Manitoba, Faculty of Social Work letterhead)

# **Are you a Foster Parent?**

**If you are a foster parent that has experienced the process of placing a First Nations child in care on medications to manage behaviors associated with a Fetal Alcohol Spectrum Disorder (FASD) and/or its associated conditions such as Attention Deficit Hyperactivity Disorder (ADHD), I would be interested to hear about your experience.**

**I am a First Nations Masters of Social Work student with the University of Manitoba calling out to those families that are willing to share their story and valuable insights.**

My research project is: **“The lived experience of Foster parents in placing First Nations children in care on medication for the management of behaviors associated with Fetal Alcohol Spectrum Disorder (FASD)”**. The purpose of this research is to gain insight from the families who have experienced the process of placing a First Nations child on medications, and hearing about their experiences while going through this process.

This research project will provide an opportunity for your experiences to be heard to gain a better insight into the processes to aid in future planning.

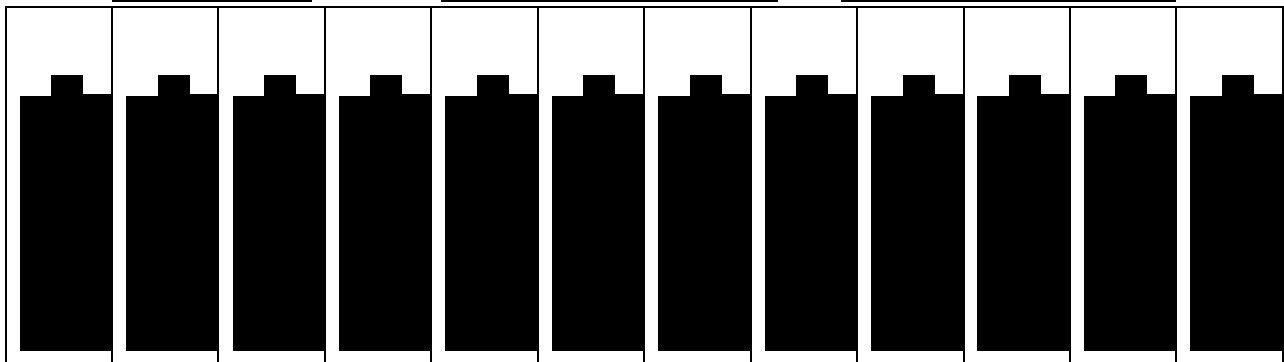
Your participation in this project is completely voluntary. All information provided will not be traced back to you and your responses will be kept confidential. If you do decide to contribute to this study, you may withdraw at any time without consequence or explanation.

A small honorarium in the form of a gift card will be provided to those family members who participate to express my appreciation for your contribution to this study.

This research project has been approved by the University of Manitoba Psychology/Sociology Review and Ethics Board.

**If you would be interested in participating in this study, please contact me at**

**[REDACTED] or email [REDACTED] OR [REDACTED]**



### **APPENDIX C: Invitation Letter to Participate in the Study**

(to be printed on University of Manitoba, Faculty of Social Work letterhead)

Dear Participant,

The purpose of this letter is to invite you to participate in a research study, the requirements for my Master of Social Work degree. This study aims to gain knowledge from the foster parents of First Nations children in Child and Family Services (CFS), who have experienced in the past or are now experiencing children being placed on medications for behaviors associated with Fetal Alcohol Spectrum Disorder (FASD) or an associated condition such as Attention Deficit Hyperactive Disorder (ADHD).

Children in care are often placed on medications for behaviors attributed to FASD, this research project aims to hear the voices of the foster parents who have had these experiences. By hearing your stories as experts in this process, we hope to gain insight into your lived experiences.

You are invited to participate in this study as it is your first-hand knowledge and expertise that is a most valuable resource for the care of children.

I am a social worker and graduate student from the University of Manitoba, and also of Aboriginal descent. Your participation is voluntary and you may withdraw from the study at any point in time. If there are questions you do not feel comfortable answering, you can refuse to answer them or withdraw from the study as a whole without consequence or prejudice. Your decision to participate, or not, will not affect your relationship in any way with the child welfare agency or resource centre with which you are associated.

Your participation and responses in this study will be kept in confidence. The agency/resource centre or anyone else affiliated with them will not be made aware of your involvement. To ensure that no one knows you participated, no identifying information will be linked back to you.

The interviews will be approximately **ONE HOUR** in length at a location that fits your needs and schedule. In addition, you will be asked to fill out a questionnaire providing some basic demographic information, as well as, the principal investigator will be taking field notes during the interview process. You will not need to prepare as it is your personal knowledge and lived experience that is of interest.

Upon completion of the research project you will be sent a brief summary of the results via email, no later than June 30, 2017.

If you would like to participate, or have questions that have not yet been answered please call or email me. If you have any questions about your participation, feel free to ask at any time, so you are informed and clear on any of the details prior your interviews.

Thank you in advance for considering participating in the interviews. If you are interested please contact Simone Richard at [REDACTED] OR [REDACTED] OR call at [REDACTED].

Sincerest regards,

Simone Richard  
Graduate Student  
University of Manitoba, Faculty of Social Work

**APPENDIX D: Summary Letter for Advertisement Posting**  
(to be printed on University of Manitoba, Faculty of Social Work letterhead)

[ENTER DATE], 2016

I am an Anishinabe woman, and have been both a foster parent and an early childhood educator for over 20 years. For the past nine years I have worked in Child and Family Services, and have supervised for over a year and a half. In 2008, I graduated with a Bachelor of Social Work from the University of Manitoba (U of M), and am currently in the thesis stage of the Masters of Social Work program.

I am in the process of completing my thesis proposal and I am seeking your approval to conduct the study. I am requesting permission to put a poster up at your facility for recruiting foster parent to be a part of a research project for completion of my Master's Degree.

First Nation children are over represented in Child and Family Services (CFS) in Manitoba. Children come to the attention of CFS agencies for many different reasons, however there are often some common factors, such as; family historical trauma, parental abuse and alcohol or drug addictions. Those high rates of alcohol addiction have led to children being born into the umbrella term, Fetal Alcohol Spectrum Disorders (FASD), often leading to life-long challenges.

In response, many First Nations children, in the care of child welfare agencies, are being placed on medications for behaviors attributed to FASD. This study will examine the processes when First Nations children are placed on medications for FASD or its related conditions, using both a brief questionnaire as well as exploratory qualitative semi-structured interviews with foster parents of First Nations children who have those conditions.

The goal is to conduct approximately 12 to 20 interviews with the foster parents. In addition, participants will be asked to fill out a questionnaire providing some basic demographic information, as well as, the principal investigator will be taking field notes during the interview process. Their responses will be kept in confidence and will not be identified to anyone other than the researchers. Any identifying comments or characteristics will be removed from any documents accessible to the public (eg; the final thesis report), in order to maintain this confidentiality.

The only individuals who will have access to the raw interview data will be myself (Simone Richard, Principal Investigator), my research assistant (to aid in transcriptions) and my U of M faculty advisor (Dr. Cathy Rocke). This research project has been approved by the University of Manitoba Psychology/Sociology Ethics Board.

By giving a voice to foster parents and learning from their lived experience in placing children in care on medications for the management of behaviors, we will be able to gain an understanding

on what this process is like when using medication as an intervention for FASD. This knowledge will help with future planning purposes, as well as informing policy.

I thank you for your consideration in this matter. If you have any questions about the research project, feel free to contact me at [REDACTED] OR [REDACTED] or call [REDACTED].

Respectfully,

Simone Richard, BSW, MSW (Candidate)

### APPENDIX E: Telephone Script

Hello my name is Simone Richard and I thank you for your interest in participating in this research project, which aims to gain an understanding of the lived experience of foster parents, who are administering medications for the management of behaviours related to Fetal Alcohol Spectrum Disorder (FASD) or a related condition to First Nations foster children.

*(I will read the following if they ask for more information about the project)*

First Nation children are over represented in Child and Family Services (CFS) in Manitoba. Children come to the attention of CFS agencies for many different reasons, however there are often some common factors, such as; family historical trauma, parental abuse and alcohol or drug addictions. Those high rates of alcohol addiction have led to children being born into the umbrella term, Fetal Alcohol Spectrum Disorders (FASD), often leading to life-long challenges.

In response, many-First Nations children, in the care of child welfare agencies, are being placed on medications for behaviors attributed to FASD. This study will examine the processes when children are placed on medications for FASD or its related conditions, using both a brief questionnaire as well as interviews with foster parents of First Nations children who have those conditions.

*(I will read this to all respondents to give them an idea about what their participation entails)*

The goal is to conduct approximately 12 to 20 interviews with the foster parents. In addition, participants will be asked to fill out a questionnaire providing some basic demographic information, as well as, the principal investigator will be taking field notes during the interview process. Your responses will be kept in confidence and will not be identified to anyone other than this researcher and her supervisor as well as research assistant. Any identifying comments or characteristics will be removed from any documents accessible to the public (eg; the final thesis report), in order to maintain this confidentiality.

Before we set up an interview time there are a few questions which I need to ask you to determine your eligibility to participate in this project.

- 1) Where did you hear about this project? \_\_\_\_\_
- 2) Are you a licensed foster parent in Manitoba?     **Yes [ ] No [ ]**
- 3) Are you a current or former foster parent of at least one First Nations (which includes Inuit or Métis) child?     **Yes [ ] No [ ]**
- 4) Was/is the child/ren in care on medications, or were going to be placed on medications for the management of behaviours associated with known or suspected FASD or a related condition? **Yes [ ] No [ ]**
- 5) Are you or your foster child part of the Berens River community, in and off reserve?  
**Yes [ ] No [ ]**

*(If they answer No to questions 2, 3 or 4 and/or Yes to question 5, then I will say the following)*



I thank you for your time but unfortunately you do not fit the requirements of this research project. Have a good day/evening.

*(If they answer Yes to questions 2, 3 or 4 and No to question 5, then I will say the following)*

Great, You fit the criteria to participate in this study. Can we set up an interview time? What date and time are you available?

Where is a convenience meeting place for you?

Thank you again.

**APPENDIX F: Consent Form**

(to be printed on University of Manitoba, Faculty of Social Work letterhead)

**Research Project Title:** The lived experience of Foster parents in placing First Nations children in care on medication for the management of behaviors associated with Fetal Alcohol Spectrum Disorder (FASD)

**Graduate Researcher:** Simone Richard B.S.W., M.S.W. (Candidate)  
Faculty of Social Work, University of Manitoba  
Supervisor, Berens River City Unit  
Southeast Child and Family Services

**Faculty Advisor:** Cathy Rocke M.S.W., Ph.D.  
Faculty of Social Work, University of Manitoba

A copy of this consent form will be left with you for your reference, and should provide you with a basic understanding of what this research project is about and what your participation will look like. Take your time to read this consent form carefully and should you have any questions, or want more details about the research, please feel free to ask.

**Purpose of the Research**

The intent of this research is to gain an understanding of the lived experience of foster parents in placing First Nations children in care on medication for the management of behaviors associated with Fetal Alcohol Spectrum Disorder (FASD), or one of its co-morbid conditions such as attention deficit hyperactivity disorder (ADHD). First we are interested in gaining some insight from their lived experiences through their stories, and secondly we are also interested in understanding both the benefits and challenges that the situation brings from their perspective.

**Research Procedure**

As a contributor in this study, you will be asked complete a brief questionnaire and then to participate in an exploratory, semi-structured interview conducted by the principal investigator (Simone Richard). During the interview process, the principal investigator will also be taking field notes to get a snapshot of the environment and of the emotions that are presented during the interview. Although this process cannot be anonymous, the researcher will ensure your confidentiality. The interview process should take approximately 1 hour to complete. The interviews will be digitally recorded and will be transcribed by my research assistant. The research assistant on the project will be knowledgeable about research confidentiality and will sign a pledge of confidentiality to ensure that the results of the questionnaires and interviews are kept confidential. The research assistant will be assisting in transcribing the digitally recorded audio interviews, as well as entering the data received from the questionnaires. They will remove all identifying information from the transcriptions and the documents will be given a respondent code.

**Risks and Benefits**

There will be no undue risks for the contributors of this study. There are a number of benefits, both to participants of the study as well as the outside community as a whole. Contributors will have an opportunity to tell their stories and personal experiences, and their valuable insight may potentially lead to policy improvements for the care of children placed on medications in the child welfare system.

**Confidentiality**

The information that you provide as a contributor will be kept in confidence and will not be identified back to the agency, or to anyone else. The only individuals who will have access to the data will be myself (Simone Richard, Principal Investigator), my faculty advisor, and my research assistant. There will be no identifying information shared about you in any of the written reports, as all responses that could be linked to you will be edited to maintain your confidentiality. There is an exception to confidentiality as if there is a disclosure of any child abuse and or neglect, whether in the past or present, I am required under the Manitoba *Child and Family Services Act* to report any such incidents to the authorities. This Act defines abuse under Subsection 1(1) as; abuse means an act or omission by any person where the act or omission by any person results in (a) physical injury to the child, (b) emotional disability of a permanent nature in the child or is likely to result in such a disability, or (c) sexual exploitation of the child with or without the child's consent. For the duration of the study all hard copy notes and transcriptions will be securely held in a locked cabinet, (in the researcher's home), and the digital audio files will be kept on a password protected computer. Following the completion of the study, all data associated with the interviews will be destroyed (expected date of completion June 2017).

**Participation and Compensation**

Your participation in this study is completely voluntary. You are free to leave the study at any point in time, for whatever reason, without penalty from the researcher or the agency. You may also refuse to answer any question in part, or as a whole. As a sign of appreciation a \$20 gift card is being offered for participating in the interview, and completion of the questionnaire.

**Interview Feedback**

The results of this study will be used to better inform practice and guide policy. Upon completion of the research, a summary of the findings will be available to you by email or mail, if you wish to obtain one. The results of this study may also potentially be featured at conferences, workshops or in refereed journal articles.

Simone Richard, B.S.W., M.S.W. (Candidate)  
Graduate Student, Faculty of Social Work, University of Manitoba

[REDACTED]

Faculty Advisor: Cathy Rocke M.S.W., Ph.D.  
Faculty of Social Work, University of Manitoba

[REDACTED]

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the researcher, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

**The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project, you may contact Pinar Eskicioglu, Human Ethics Coordinator at 474-7122 or [humanethics@umanitoba.ca](mailto:humanethics@umanitoba.ca). A copy of this consent has been given to you to keep for your records and reference.**

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**APPENDIX G: Demographic Form**

(to be printed on University of Manitoba, Faculty of Social Work letterhead)

***“The experience of Foster parents in placing First Nations children in care on medication for the management of behaviors associated with Fetal Alcohol Spectrum Disorder (FASD)”?***

The demographic information requested on this form will support data analysis of the study. Please ensure that each question is answered. All information on the demographic form will be kept confidential in a separate file.

1. How long have you been a foster parent? \_\_\_\_\_
2. How many children have you fostered with a FASD or suspected? \_\_\_\_\_
3. Does your foster child have a formal diagnosis? \_\_\_\_\_
4. What was the age of the child when placed on medications? \_\_\_\_\_
5. Current occupation? \_\_\_\_\_
6. Are you employed full time: [  ] or part time: [  ]
7. What do you identify as your ethnicity? \_\_\_\_\_
8. Number of family members in your household: [  ]
9. Who determined the need for medication? \_\_\_\_\_
10. What medication is your foster child currently prescribed? \_\_\_\_\_

**APPENDIX H: Interview Questions – Foster Parents**

1. Tell me about the process that you experienced when placing the child on medications?
2. Who influenced the decisions regarding medication as an intervention?
3. Has there ever been a decision for the child/youth to be taken off medication and who decided?
4. Have you ever experience difficulty when giving the child/youth medication? (Allergic reactions, extreme side effects, refusal, etc)
5. What is your view regarding medications?
6. What was life like before medication?
7. What has life been like now when using medication?
8. Tell me about what this overall experience has been like for you?

## **APPENDIX I: Resources for Participants in Distress**

(to be printed on University of Manitoba, Faculty of Social Work letterhead)

### **Aurora Family Centre**

5<sup>th</sup> Floor – 491 Portage, University of Winnipeg

(204) 786-9251

Various services, no cost for service.

### **Klinik Community Health Centre**

870 Portage Avenue

(204) 784-4090

In-person counselling, walk-in hours with no cost for service.

### **Klinik Crisis Line**

(204) 786-8686

Anyone in distress of any kind may call this 24 hour crisis line.

### **University of Manitoba: Psychological Service Centre**

161 Dafoe Building, University of Manitoba

(204) 474-9222

Clinical therapy and assessments, some evening hours, no charge for services, space is limited.

### **APPENDIX J: Oath of Confidentiality**

(to be printed on University of Manitoba, Faculty of Social Work letterhead)

*As a part of working with the research project “The experience of Foster parents in placing First Nations children in care on medication for the management of behaviors associated with Fetal Alcohol Spectrum Disorder (FASD)”, you are required to sign the oath below and ensure that the signed document is stored in the research files for this study.*

The principal investigator on this study is: Simone Richard

1. I understand and agree that I have an ethical and legal duty to maintain strict confidentiality of all information obtained from research participants and all of their data and records.
2. I agree to safeguard the identity of all research participants from unauthorized persons so as to prevent direct or indirect identity disclosure.
3. I understand and agree that research related documents must be held secure in locked storage or in password protected files on a password protected computer.
4. I agree to hold in strict confidence the discussion of all research matters unless specifically instructed otherwise by the principal investigator.
5. I agree not to publish or make public any information arising from research except as reviewed and approved by the principal investigator.
6. I fully understand the penalties for breach of this Oath

Name of Researcher: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness: \_\_\_\_\_

Signature of Witness: \_\_\_\_\_ Date: \_\_\_\_\_



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