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Narrative Study of Educational Stigmatization in Parents of Indigenous Children with FASD

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College of Social and Behavioral Sciences

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Wendy Sherren-Doucette

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Walden University
2021

Abstract

Narrative Study of Educational Stigmatization in Parents of Indigenous Children with
FASD

by

Wendy Sherren-Doucette

M.Ed., University of PEI, 2005

B.Ed., University of PEI, 1981

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Psychology
Educational Psychology

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Abstract

Often public stereotyping and prejudicial attitudes follow parents of Indigenous children with FASD throughout their day-to-day life. Stigma affects Indigenous people, particularly parents of Indigenous children with FASD, in different facets of their lives. The purpose of this study was to explore the perceptions that parents of Indigenous school-aged children with FASD have had of their experiences with school personnel. The study was grounded in Goffman's social stigma theory and used a narrative inquiry approach in an interview-style format which collected data for this study. The research question explored the experiences of six parents of Indigenous children with FASD with the education system. The findings showed that prejudice, stigma, bias, and racism were prevalent in their experiences, and the effects of intergenerational trauma from residential schooling and colonization have led to stereotyping, exclusion, and discrimination. The findings from this study may support other parents experiencing difficulties with the education system and assist them with their child's transition to the school system and interaction with educators. Improving these transitions, along with helping other community members understand the challenges that must be overcome, will help create a positive social change in the community.

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Dedication

I would like to dedicate my dissertation to my family, in particular to my children, Nicholas, Rebecca, and Thomas, who believed in me and supported me throughout the entire process. Thank you for your support and love that helped keep me focused and determined to complete this study. I would also like to dedicate this to my parents, especially my father who believed that I could do anything I put my mind to. I know he is looking down at me and smiling at my achievement.

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Chapter 1: Introduction to the Study

The forced assimilation in Canada of the Indigenous people has had a severe impact on many aspects of their lifestyle. This includes the identity and mental health of Indigenous people. The dynamics and overall structure of communities, bands, and nations are related to colonization and residential schools. All of these factors join together to help explain the educational stigma that Indigenous parents with children with Fetal Alcohol Spectrum Disorder (FASD) face in their daily lives. In Canada, it has been well-documented that discrimination, racism, and stigma adversely affect the health and well-being of the Indigenous people (Aspler et al., 2019).

According to Firestone et al. (2015), cycles of family disruption, abuse, colonization, dislocation from traditional lands, and outlawing of spiritual practices among Indigenous people has led to many health and social inequalities in Canada. There are many factors, such as lack of awareness and education, unwelcoming environments, and negative experiences, that have pointed to stigmatization felt by the Indigenous negative stereotyping, which has gone along with prejudice, discrimination, and the devaluation of a person.

Link and Phelan (2001) stated that stigma exists when elements of labeling, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows these processes to unfold. Stigma is reliant on power. Stigma rests on cultural patterns of behaving, thinking, and feeling that are also partly determined by the social discourse, as well as the power structures surrounding a particular group of individuals (Bell et al., 2016). The historical trauma of Indian residential schools (IRS) has had

ongoing intergenerational effects on the psychological well-being of Indigenous peoples and their communities (Boska et al., 2015).

The stigma felt by Indigenous peoples, specifically Indigenous mothers, is compounded by the fact that they are often monitored and scrutinized as the assumption is made that they pose a dangerous threat to the future of their unborn child (Inman, 2019). This stigma has stemmed from the perspective that women who give birth to children diagnosed with FASD have made deliberate choices during pregnancy that placed their unborn child at risk (Shankar, 2016). Further, this stigma often overflows into the school system as Indigenous parents face various challenges when their child enters school.

Problem Statement

Parents of Indigenous children with FASD face many challenges in their daily encounters with family, school, and the community at large. These challenges and struggles are often related to the stigma and discrimination that they must overcome to handle their encounters throughout the day. Parents of children with FASD often feel burdened by the difficulties of handling their everyday family life, social isolation, and worry for their child's future (Helgesson et al., 2018). Experiences of stigma are often one of the most significant barriers that one must overcome to have a satisfying life. The fundamental labeling that has been associated with stigma tends to lead to reductionism on the person as a whole (Bell et al., 2016). Bell et al. (2016) also stated that there is very little literature that examines the public attitudes or the experiences of negative judgements across the life course for individuals with FASD and their families. Swart et

al. (2014) stated that biological mothers of children with FASD had feelings of self-blame for their child's disorder. In addition, Swart et al. posited that research directed at examining caregivers' perspectives about how they managed the education of school-aged children with FASD was scarce. In the study conducted by Swart et al., it was noted that the strategies and tactics used by caregivers to fit in resulted in them experiencing despair, disconnection, and the feeling that their children were shunned and isolated. According to Aspler et al. (2019), more research should be considered to better understand the communication of FASD and alcohol especially in the context of stigmatization and stereotyping of Indigenous peoples.

The impact of the FASD label has spread beyond the individuals themselves since a diagnosis of FASD, which can be a catalyst for stigmatization, may also tell us something about a biological mother's behavior (Aspler et al., 2018). Aspler et al. (2018) also stated that by merely focusing on the effects of fetal alcohol exposure, social problems related to harmful drinking, such as economic and social inequality and social marginalization, are turned into a problem for the individual. This stigma is often caused by public attitudes or underlying beliefs about FASD, and the parents of children with FASD often lack knowledge, understanding, and support (Bell et al., 2016; Helgesson et al., 2018). According to Bell et al. (2016), stigma is best understood as a process that involves the endorsement of negative stereotypes, accompanied by prejudice, including emotion-based reactions, and potential discrimination or devaluation of persons.

By exploring the parents of Indigenous school-aged children with FASD's perceptions of their experience with school personnel and examining if those perceptions

included stigmatization, the results of my study have the potential to allow other Indigenous parents in similar situations to have a better understanding of the trauma, difficulties, and challenges that they face at school. By helping other parents of Indigenous children with FASD understand the experiences they encounter, my study may facilitate a smoother transition to and through school. Improving this transition, along with helping other community members understand the challenges that must be overcome, will help create positive social change in the community.

The connection between labels and stereotypes has been a significant aspect of the psychological study of stigma (Link & Phelan, 2001). The need to explore the issue of stigma and discrimination as well as addressing the issues centered around this negative stereotyping was posited by Masotti et al. (2015) as a gap in the research that needs to be filled. Bell et al. (2016) also pointed out that it is vital to research the long-term effects of negative public attitudes toward people with FASD and their mothers. These gaps in research affect Indigenous people with FASD and their mothers (Samaroden, 2018). The knowledge gained by exploring the experiences of parents of Indigenous children with FASD helps fill the gap in knowledge and awareness that contributes to the educational stigma that impacts their lives.

Purpose of the Study

The purpose of this study was to explore the parents of Indigenous school-aged children with FASD's perceptions of their experience with school personnel and to examine if those perceptions of their experience included stigmatization. As previously stated, research showed the importance of being aware of the complexity that their

experience with school personnel, including any experience of stigmatization, may have on parents of Indigenous children with FASD, and by using a narrative inquiry study, the gap was addressed. These negative attitudes and beliefs about FASD cause feelings of shame, blame-putting, and guilt to parents and children associated with FASD. Bell et al. (2016) stated that large knowledge gaps limit our understanding of how labels or public attitudes that are enacted through prejudice and discrimination impact the experiences of children with FASD and their parents. For children with FASD, negative stereotypes and beliefs on the part of peers and educators could accompany the difficulties faced in school because of their disability (Bell et al., 2016)

The operation of IRS is one social injustice system that leads to the educational stigmatization of Indigenous students. Students from IRS have reported greater depressive symptoms associated with stressors, such as childhood anxiety, adult trauma, and perceived discrimination, along with higher rates of alcohol and drug use (Boska et al., 2015). The stigma that occurs within the education system starts at an early age and continues as they move through the different grade levels. Schools are the central institutions for learning about oneself and others, acquiring positive socialization skills, and building healthy relationships (Masotti et al., 2015). Residential schools are only one recent example of forced assimilation in Canada, the effects of which are still being felt today through the different generations of Indigenous people.

The stigma surrounding FASD has been identified as an important issue for both the individual affected with FASD and the woman who gave birth to them (Aspler et al., 2019). Aspler et al. (2019) also reported that FASD remains poorly understood by

Canadians, which could contribute to reported stigma faced by both people with FASD and women who drink alcohol while pregnant. In their review of various newspaper articles, Aspler et al. stated that the way media represent Indigenous women of children with FASD is inaccurate and exaggerated and these representations can lead to harmful stereotyped beliefs about Indigenous people.

By gaining a better insight into the parents of Indigenous school-aged children with FASD's experiences with school personnel, other parents in the same situation can discover ways in which to maneuver through the school system to make the process for their child smoother. Determining best practices to ensure that the proper supports are in place, as well as establish structural supports for parents of Indigenous children with FASD, is essential to help address stigmatization in the education system. These experiences could help guide other Indigenous parents to advocate for their children in the school system in a timely and practical manner.

Research Question

RQ – Qualitative – How did parents of Indigenous school-aged children with FASD describe their experiences with school personnel?

Theoretical Framework for the Study

The theoretical framework for this study evolved around Goffman's (1963) theory of social stigma. The effects of colonization on Indigenous people are traumatic, causing intergenerational trauma, which are compounded by the stigma towards mothers who drink during pregnancy and the stigma toward the person with FASD (Samaroden, 2018). Intergenerational trauma from the residential school system and other colonial policies

contributes to widespread alcohol and other substance abuse in some Indigenous communities and individuals (Banerji & Shah, 2017). In 1963, Erving Goffman developed his theory of social stigma, which studied the views of what it is like to be a stigmatized person in society. His definition of a stigmatized person was one who is not fully accepted by society and may be considered abnormal, different, or one who is continually trying to acclimatize to how one should look and act in society.

Children with FASD are often stereotyped as different from the norm, lazy, and even violent, with difficulties relating to attention, learning, and social relationships (Morrison et al., 2019). The cognitive impairments, such as attention deficits, intellectual delays, and diminished intellectual functioning, that are seen in childhood can be translated to academic failure, substance abuse, mental health problems, contact with the law enforcement, and an inability to live independently and obtain/maintain employment (Popova et al., 2017). Goffman's (1963) theory is further explained in the following chapter and shows the relevance of the perceptions of parents of Indigenous children with FASD as well as explores the feelings of perceived stigmatization from the school personnel.

Nature of the Study

The nature of this study was to explore the perceptions that parents of Indigenous school-aged children with FASD have of their experiences with school personnel and examine if those perceptions of their experiences included stigmatization. A narrative inquiry approach was used to explore and describe the phenomena. Bell et al. (2016) stated that a narrative approach adheres to the storytelling approach used by Indigenous

people to recount their events and traditions passed on through the generations as well as aligns with their worldviews; therefore, a narrative approach was used to describe the perceptions that parents of Indigenous school-aged children with FASD have of their experiences with school personnel and examine if those perceptions of their experience include stigmatization. The narrative approach is particularly useful when there is a need to obtain an in-depth appreciation of an issue, event, or phenomenon of interest in its natural, real-life context (Crowe et al., 2011). As the phenomenon of interest for this study was the educational stigma of parents of Indigenous school-aged children with FASD, the narrative approach was best suited for this study.

The collection of rich, descriptive data may help create a positive social change in the community and with other Indigenous parents in similar situations by helping them gain a better understanding of the personal experiences encountered in the educational system. Open-ended, semi-structured questions were used in an interview format in a comfortable setting suitable for both the participants and the researcher. The information collected was recorded and transcribed verbatim to provide an accurate account of their experiences. All information has been kept confidential and in a safe, secure place.

Definitions

Alcohol-related birth defects: The term alcohol-related birth defects was previously referred to as FAE. It is the diagnostic classification for individuals who were prenatally exposed to alcohol and have physical abnormalities such as malformations of the heart, bone, kidney, vision, or hearing systems (CDC, 2019).

Alcohol-related neurodevelopmental disorder: The term alcohol-related neurodevelopmental disorder (ARND) was previously referred to as FAE. It is the diagnostic classification for individuals who were prenatally exposed to alcohol and have symptoms of central nervous system damage associated with FAS but do not present the facial features typical of FAS (CDC, 2019).

Fetal alcohol effects: The term fetal alcohol effects (FAE) was previously used to describe intellectual disabilities and problems with behavior and learning in a person whose mother drank alcohol during pregnancy but has since been replaced with the terms ARND and alcohol-related birth defects (CDC, 2019)

Fetal alcohol spectrum disorder: Fetal alcohol spectrum disorder (FASD) is an umbrella term for a variety of impairments experienced by individuals who are exposed to alcohol in utero (Shankar, 2016). FASD is a complex and multifaceted disease, which is not just linked to alcohol consumption but also the environment and socioeconomic status (Shankar, 2016).

Fetal alcohol syndrome: Fetal alcohol syndrome (FAS) is a condition in a child that results from in utero alcohol exposure during the mother's pregnancy which causes brain damage and growth problems that vary from child to child, but the defects caused by FAS are not reversible (Mayo Clinic, 2018).

First nations people: First nations people is a term used to identify Indigenous peoples of Canada who are neither Metis nor Inuit and also includes both status and non-status Indians (Indigenous Corporate Training Inc [ICTI], 2019).

Indigenous peoples: Indigenous people is a collective name of the original people of North America and their descendants.

Intergenerational trauma: Intergenerational trauma, or transgenerational trauma, is what happens when untreated trauma-related stress experienced by survivors, such as IRS survivors, is passed on to second and subsequent generations (Berube, 2018).

Microaggression: Microaggressions are the everyday verbal, nonverbal, and environmental slights, snubs, and insults, whether intentional or unintentional, which communicate hostile, derogatory, or harmful messages to target persons based solely upon their marginalized group membership (Wing Sue, 2010).

Residential school syndrome: Residential school syndrome is a suggested term used for survivors of the IRS in Canada. The proposed diagnostic features of residential school syndrome are similar to the diagnosis of post-traumatic stress disorder, but with specific cultural impact (Brasfield, 2001).

Assumptions

Assumptions are so underlying that, without them, the research problem itself could not exist (Simon, 2011). The data collected in this study were based on the educational stigmatization experiences of parents of Indigenous children with FASD. The primary assumption was that parents can give accurate accounts of the educational stigma that they encountered with their child at the school level. I assumed that the data collected was probably accurate and the educational stigma that was endured by the parents of Indigenous children was accurately recounted.

Scope and Delimitations

The participants for this study are limited to Canadian parents of Indigenous children with FASD that were stigmatized by members of the educational system. This study only included Indigenous children and did not include other ethnicities. This study only included Indigenous children with FASD and did not include other disabilities or non-Indigenous children with FASD.

Limitations

The study only included parents of Indigenous children with FASD. This study is not generalizable to people of other ethnicities.

Significance

There has been a significant amount of literature on FASD among Indigenous peoples. Over the past few years, studies have been done on FASD and the effect it has on both Indigenous and non-Indigenous peoples. Still, more is needed on the educational stigma felt by Indigenous peoples. The research done in this study filled a gap by exploring the educational stigma that is felt by parents of Indigenous school-aged children of FASD. This study was unique as it focused on an under-studied area, but one that has been much needed. The impact that educational stigma has on Indigenous families is complex and multi-faceted. The inferior education provided to these students as well as their harrowing experiences of guilt, shame, and punishments amplify the trauma that they experienced (Hansen, 2008). This trauma manifests throughout the generations has led to the intergenerational trauma felt by many Indigenous peoples. The results of this study provided insight into the possibility of educational stigma felt by

parents of Indigenous school-aged children with FASD and provided additional information that complements the body of research that addresses educational stigmatization as well as provides support to other parents that experience similar situations.

Summary

The purpose of this chapter was to introduce the study by providing background information related to the study. A review of the literature is in Chapter 2. The literature review supports the root of the study in the existing research and identifies the gap. This study provided insight and support for parents of Indigenous school-aged children with FASD.

Chapter 2: Literature Review

Introduction

The broad spectrum of the stigma, or negative stereotyping, that is often found in Indigenous communities results in discrimination, judgmental attitudes from service providers, feelings of shame, low self-esteem, and the fear of having their child taken away from them. Many people affected by FASD feel judged by others, which often prevents them from seeking services that contribute to an improved quality of life (Green et al., 2018). Various studies noted that gaps in research exist regarding the long-term negative public attitude affecting Indigenous people with FASD (Samaroden, 2018). Studies have shown that research on FASD remains a critical and valuable endeavor to improve the lives of Indigenous children with this condition and their families (DiPietro & Illes, 2014). Samaroden (2018) further noted that any research done on the Indigenous should use a narrative inquiry as it would align significantly better with the Indigenous worldviews. By taking a narrative inquiry approach, I supported the predominance of storytelling in Indigenous culture. As this study was based on the parents of Indigenous school-aged children's experience with school personnel, using a narrative inquiry approach was the best way to conduct the research. A narrative inquiry approach provided the opportunity for in-depth analysis.

The purpose of this study was to explore the experiences of Canadian parents of Indigenous school-aged children with FASD with school personnel, as well as examine if their perceptions of their experience included stigmatization. FASD is recognized as an essential health concern and a leading cause of mental deficiency, as well as a

developmental delay among North Americans (Bell et al., 2016; Popova et al., 2017). As a result, FASD has emerged as a public health priority in Canada (Pei et al., 2017).

Although FASD is found in all socioeconomic and ethnic groups in Canada, it is more commonly found in more impoverished communities with a high prevalence of drinking. In particular, FASD has been observed at high rates in select First Nations and Inuit communities in Canada (Nash et al., 2018). FASD is known in Canada as an affliction that affects significantly more Indigenous people than non-Indigenous people (Samaroden, 2018).

Search Criteria

The sources used to conduct the inquiry included journals, books, Public Health organizations, and the Truth and Reconciliation Commission. For my search, I employed the following databases: Thoreau Multi-Database Search, MedLine, ProQuest, Education Source, ERIC, EBSCOhost, SAGE Journals, and PsycINFO. My search also included looking at dissertations and Indigenous websites that included information on FASD and residential schools in Canada. Keywords and phrases included and not limited to were: *Aboriginals, Indigenous people, First Nations, residential schools, residential school intergenerational impact, residential school survivor, social stigma, educational stigma, intergenerational trauma, Fetal Alcohol Spectrum Disorder, prenatal alcohol exposure, Indigenous children with FASD, gin epidemic, alcohol consumption, alphabet soup, on the land, bullying in schools, microaggression, perception, and Goffman's Social Stigma Theory*. From this search, I selected articles that represented compelling information on how FASD impacts the Indigenous people via educational stigma, as well as the history

of FASD and residential schools. Limitations were set to include all articles written in the past 5 years, though some articles that were chosen were written before the past 5 years. These articles contained information that was found in recent studies.

Theoretical Framework

The issue of stigma in public discourse has been attributed to Goffman (1963), who identified stigma as of a physical nature, associated with character or within-group identity, and related to society's need to categorize people. Stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them; it takes power to stigmatize as it is entirely dependent on social, economic, and political power situations (Link & Phelan, 2001).

Stigmatization has a profound impact on different areas such as a person's earnings, housing, criminal involvement, health, and overall life. Stigmatization has negative consequences, such as mistrust, low self-esteem, isolation, and fear, and affects the behaviors of individuals. As stigmatization occurs when people are labeled, set apart, and linked to undesirable characteristics, people often experience status loss, racism, and discrimination (Link & Phelan, 2001). Given the importance of perception, stereotyping, and discrimination, Goffman's theory of social stigma was used to understand how parents of Indigenous children with FASD feel about themselves with the education system and society in general.

Ajzenand Fishbein's (1973) theory of reasoned action (TRA) is used to predict behaviors, especially discriminatory ones. According to TRA, behavior is predictable in terms of the individual's attitudes towards performing the behavior in question, through

the intervening effect of behavioral intention (Al-Suqri & Al-Kharusi, 2015). According to Al-Suqri and Al-Kharusi (2015), this theory also postulated that a person's intentions about performing a behavior (which ultimately determines whether they would do so) are influenced by social pressures or "subjective norms," which arise from their perceptions of what others think about them performing the behavior in question. TRA maintains that coercion and intention predict behavior and a person's behavior is determined by their behavioral intention to perform it (Fishein & Ajzen, 1975). Even though this theory revolves around discriminatory behaviors and behaviors influenced by social pressures, it does not correlate with the stigma felt by Indigenous people and does not align with the research for this study.

Another theory that was looked at was Tajfel and Turner's social identity theory. This theory was introduced to explain intergroup behavior. Tajfel and Turner (2004) proposed that the groups which people belong to are an important source of pride and self-esteem and that group are divided into "in" groups and "out" groups. In-groups are the groups one identifies with, and out-groups are those that one does not identify with and might discriminate against (McLeod, 2008). There are some aspects of this theory that can be used to help identify the discrimination and racism felt against Indigenous people, but Goffman's (1963) social stigma theory was chosen as the framework for this study. Bell et al. (2016) stated that negative beliefs and attitudes including experiences of discrimination are often the tipping points for a generation of stigma.

Fetal Alcohol Spectrum Disorder

Poole et al. (2016) stated that FASD describes the range of harms that result from prenatal alcohol exposure and are the leading cause of preventable developmental disability among Canadians. FASD was first noted in France by Lemoine and later identified through the work of Jones and Smith in 1973. Alcohol consumption during pregnancy can result in the development of FASD, which is recognized as an important health concern and, according to Popova et al. (2017), a leading cause of mental deficiency among North Americans. Popova et al. (2017) stated that the prevalence of FAS and FASD among the Indigenous population in Canada is estimated to be 38 times and 16 times higher, respectively, than the general population in Canada.

Before the use of the term FASD, the wide-ranging outcomes which result from prenatal alcohol exposure were described as a complicated “alphabet soup” of terms (Gray, 2017). In the 1700s, during the “gin epidemic” in England, children born to alcoholic mothers were described as weak, feeble, and distempered. During the late nineteenth century and early twentieth century, alcohol was linked to many of the alleged hereditary damages that were passed down between generations and were thought to result in heritable imbecility (O’Neill, 2011). This widespread belief that alcohol consumption by men and women predisposed their offspring to social vice was one reason why the temperance movement, a social movement created to promote awareness against the use of alcoholic beverages, gained popularity and prominence in the early twentieth century (O’Neill, 2011). By the 1920s when prohibition was introduced, the issues of prenatal alcohol exposure and birth defects were ignored until later years. After

the repeal of prohibition in 1933, the perception of alcohol went from a vilified and harmful poison to a more benign agent. It was even recommended by some doctors as a means of social relaxation with beneficial effects (O'Neill, 2011). Doctors also used intravenous alcohol treatments to delay preterm labor in some women (O'Neill, 2011).

The first suggested case reports of congenital disabilities associated with prenatal alcohol exposure were described in France by Dr. Paul Lemoine, a French pediatrician (Millar et al., 2017). Lemoine and his colleagues looked at 127 cases of children who had been exposed to alcohol prenatally and later experienced many difficulties such as mental health disorders, disrupted school experiences, trouble with the law, and addictions. The study done by Lemoine and his colleagues did not set out the diagnostic features required to identify this condition (Mukherjee et al., 2012). The diagnostic criteria were established a few years later by American pediatricians, Dr. David Smith and Dr. Kenneth L. Jones, who specialized in dysmorphology.

In 1973, Smith and Jones reported on children living on an American Indian reserve who all presented with consistent, common, and recognizable features, which they called FAS. This period in which FAS was classified influenced the definition and discovery of the defects (O'Neill, 2011). From this report, they set out a series of criteria that formed the basis for the development of diagnostic criteria for FASD (Mukherjee et al., 2012).

FASD is described as a “hidden disability” in part because there are often no overt physical signs to quickly identify an affected child (Millar et al., 2017). The symptoms associated with FASD are not always interpreted as FASD; therefore, children with

FASD are diagnosed with another disability. According to Dej (2011), FASD was believed to be the first illness that physicians considered with Indigenous patients, while in contrast, non-Indigenous people were more likely to be diagnosed with attention deficit-hyperactivity disorder (ADHD). At present, a diagnostic team is now required to diagnose a child with FASD. In Indigenous communities, the inclusion of a traditional healer or elder as part of the team is recommended. Indigenous traditional healers help foster a cultural connection while interpreting the meaning of FASD in a cultural context to both parents and children and providing them with lifestyle and vocational guidance (Banerji & Shah, 2017). Most communities do not have the diagnostic resources for FASD; therefore, their children are often not diagnosed with FASD but said to have ADHD or autism. To be diagnosed with FASD, a confirmed history of prenatal alcohol exposure needs to be determined. FASD is frequently associated with ADHD and sleep disturbance, which both can compound learning difficulties (Banerji & Shah, 2017).

It is important to recognize the identification of any secondary disabilities, along with primary disabilities associated with FASD, that might have developed (Alton & Evenson, 2006). According to Alton and Evenson (2006), the effects of secondary disabilities can be minimized with early intervention. These secondary disabilities, such as mental health problems, trouble with the law, and drug and alcohol problems, are often connected in part to discrimination, historical influences, and broader health and social development issues (Wilson, 2013). The prevention and identification of FASD can also be influenced by stigma (Bell et al., 2016).

As children affected by prenatal alcohol exposure approach adolescence, they are at an increased risk of developing secondary disabilities, such as school failure and dropout, mental health problems, sexually deviant behavior, alcohol and other drug problems, unemployment, homelessness, and involvement with the criminal justice system (Popova et al., 2016). Children with FASD require special education services. In addition to providing these children with special services and interventions, further knowledge is needed to further the educational needs of students with FASD and create strategies for teaching these students. Physical, cognitive, and behavioral effects of prenatal alcohol exposure are challenging to Indigenous children and their parents and have varying impacts on their lives. Factors such as chronic emotional distress, shame, mistrust, and impaired relational capacity have a substantial adverse impact on many families, which continue to be passed on through the generations (Barnes & Josefowitz, 2019).

Often children diagnosed with FASD are labeled as having behavioral problems, such as hyperactivity, outbursts, and aggressive or defiant behavior extending into adulthood. These behavioral problems that are seen in early childhood often transform into other issues such as inability to keep a job, trouble with the law, substance abuse, and mental health problems (NOFAS, 2019). The challenges that children with FASD face extend beyond their specific cognitive impairment, and this, in turn, has a major impact on them in later years.

The first reported case of FAS in Canada was in British Columbia in the late 1970s, though it did not state the ethnicity of the child. Since that time, public education

campaigns have been delivered to prevent FAS. Based on early experiences in meeting the complex needs of children with FASD, the Winnipeg School Division (WSD), Manitoba, established one of the first classrooms for children with FASD in Canada in 1995 (Millar et al., 2017). The WSD recognized that the needed approach to educating children with FASD meant learning how to adapt and individualize the educational environment and academic program to address their specific learning profiles (Millar et al., 2017).

These children face considerable challenges with sensory difficulties and academic and adaptive achievement. Their challenges go beyond their specific cognitive impairments. Over the years, the WSD program for children with FASD has expanded to a coordinated systems-level approach that has worked closely with health care professionals, local government, and non-government professionals and has made the WSD a North America leader in FASD education (Millar et al., 2017).

Millar et al. (2017) noted in their study that school based FASD programs not only address the educational needs unique to children with FASD but also help decrease stigma. The different types of stigma experienced include the effects of self-stigma experienced by students with FASD, stigma experienced by parents/family, and stigma among the general population. School systems need to adapt educational practices and policies to support the needs of children with FASD. Although Winnipeg has the largest Indigenous population of any major city in Canada, the research did not state the ethnicity of the children involved in the FASD school-based programs.

Effects of Alcohol on Indigenous Mothers

Substance abuse among pregnant and parenting women has continued to be a major health concern in Canada with the highest rate being found in the Indigenous population (Niccols et al., 2010). Based on a synthesis of Canadian data, FASD has been higher in Indigenous than non-Indigenous people in Canada (Werk et al., 2013). According to Niccols et al. (2010), substance abuse offered a means of coping with trauma, such as childhood abuse, partner violence, and the intergenerational effects of colonization. Social stigma has also been reported as an influence on an Indigenous' self-identity, as well as their recovery. Public discourse and health messages that emphasized blame, shame, and a mother's responsibility fed into stereotyped portrayals of women who drank while pregnant as unfit, irresponsible, and even criminally negligent mothers (Aspler et al., 2018). Although it has been noted that Indigenous mothers are at high risk, there has still been limited research in the outcomes of addiction treatment.

Many of the social determinants of health have been known to influence a women's likelihood of consuming alcohol during pregnancy and overlapped with the risk factors for FASD (Flannigan et al., 2018). Pregnant women who drank alcohol often experienced judgmental attitudes from society in general, feelings of shame, depression, low self-esteem, and fear of losing their children. Negative attitudes of healthcare providers and responses that stigmatized Indigenous women have deterred them from accessing care (Niccols et al., 2010). FASD is mired in stigma. The stigma against women who gave birth to children with FASD and the children with FASD is

widespread. This stigma has often been noticed when the children started school and experienced difficulties in and out of the classroom.

The mothers of children with FASD have been targets of stigma, sometimes seen as failures as mothers, which in turn impacted on them disclosing information, seeking help, or from receiving adequate medical care. Stigma further complicated the understanding of this disorder and the support needed by these mothers. This stigma and guilt has also affected the interaction that Indigenous mothers have had with the school system.

The availability of culturally appropriate services has been a significant concern for Indigenous women accessing treatment in Canada (Niccols et al., 2010). These Indigenous women faced unique difficulties accessing mental health and addiction services and this has harmed the mental health of Indigenous people. Indigenous women have found that accessing adequate healthcare and preventative services was problematic, as well as the negative stereotyping that was felt towards them.

According to NOFAS (2019a), prenatal exposure to alcohol has significantly impacted the development of the child, as well as the parenting challenges faced by Indigenous mothers with substance abuse issues. Overall, parents of Indigenous children with FASD stated that people did not understand what they have faced and this lack of knowledge about FASD has often been seen when parents attempted to get the necessary support that they needed, whether it was in the educational system or healthcare system (Bell et al., 2016). Educators often did not know how to provide the necessary support in the classroom, thus, making the right interventions that were necessary to be put in place

almost non-existent. The public attitudes towards women who drank during pregnancy have had a tremendous impact on how societies understood, perceived, and supported them.

The poverty, mental health challenges, substance abuse, and other struggles faced by Indigenous people stemmed from colonial policies and practices, such as a residential school system where children were removed from their families and placed in Indian residential schools. These actions have had a profound impact on the people and has continued to be felt through the generations. Intergenerational trauma from the residential school system and other colonial policies has contributed to widespread alcohol and other substance abuse in some communities and individuals; however, not all individuals who had these exposures abused alcohol (Banerji & Shah, 2017). Indigenous women who attended residential schools, as well as their children, have felt the effect for many years. In many cases, the cycle of violence, alcohol and drug abuse for the abused and the abusers are seen to have been caused by the shame and guilt that was inflicted on them during their time in the residential schools (Corrido & Cohen, 2003). Not knowing how to deal with this shame and guilt, it trickled down to the different generations as they expressed their anger, shame, and frustration on members of their own family (Corrido & Cohen, 2003).

Indian Residential Schools

Through the various investigations done by government and other sources, the conclusion was that Indian residential school (IRS) in Canada exposed thousands of Indigenous students to horrific experiences (Truth and Reconciliation Commission of

Canada, 2015). According to Barnes and Josefowitz (2019), these experiences contributed significantly to the present state of welfare of many Indigenous children, including their educational and economic success. It has also jeopardized their languages and cultures, as well as creating health problems and the overrepresentation of Indigenous peoples in the criminal justice system (Barnes & Josefowitz, 2019). The trauma caused by the residential school system, including physical and sexual abuse, perpetuated a culture that consumed alcohol, leading to an increase in Indigenous children with FASD (Eni & Senecal, 2009; Samaroden, 2018). Over 150,000 Indigenous children were forced to live at the residential schools from the 1870s to the mid-1990s, where various forms of neglect and abuse took place.

Many Indigenous parents had their children taken from their homes, put on a boat, and sent to a school away from their community, their culture, and their family. To these children, they were now in a different world where they had no identity, a language barrier, and a vast cultural difference. The trauma they faced during this dire time has still been felt for generations. The experience of trauma in one generation influenced subsequent generations, a perspective that seemed to have resonated in the literature related to Indigenous health, as well as among Indigenous peoples who lived with the historical, collective traumas experienced by their ancestors (Bombay et al., 2014). As seen in today's generation, the damage that was done by residential schools has affected many generations. Generations of abuse in residential schools left an infamous legacy for Indigenous communities (Schissel & Wotherspoon, 2002). Many Indigenous children

who attended residential schools were bullied and abused, leading to a burden of shame and anger that was felt throughout the rest of their lives.

Parenting skills were deeply affected by the events that took place at IRS. The effects on parenting appeared to develop through a decrease in health and socioeconomic factors that came from the IRS experiences. The trauma caused by the residential school system perpetuated a culture that consumed alcohol, leading to an increase in Indigenous children born with FASD (Bell et al., 2016). Some have suggested that the experiences that these Indigenous students went through were a unique form of post-traumatic stress disorder called “residential school syndrome” and the children went through what has often been phrased as “historical trauma. “ While related to post-traumatic stress disorder, residential school syndrome has been characterized by an “intense silence and a great fear of feeling” (Corrido & Cohen, 2003). The purpose of the residential schools was to sever the link between Indigenous parents and their children, and for generations, Indigenous children were cut off from their families. Survivors of the residential schools created the phrase “residential school syndrome” to describe their deep sense of isolation, pain, and shame, and their inability to show or to feel love (Loyie, 2014).

Many children alleged psychological, physical, and sexual abuse during their residential school attendance, and many of those now-adult survivors claimed to have had a continuing negative impact of their experience in which this impact has come to be called “residential school syndrome” (Brasfield, 2001; Wilk et al., 2017). The concept of “historical trauma” suggested that the effects of these disruptive historical events are collective, affecting not only individual survivors, but also their families and

communities (Wilk et al., 2017). This concept was also suggested in the report done by the Truth and Reconciliation Commission of Canada (2015) which stated that the survivors of the residential schools were not the only ones who had their lives disrupted. These experiences also affected all members of their family including their partners, their children, their grandchildren, their extended families, and their communities. This trauma is still felt today in many communities.

The children who attended these schools were exposed to a strict, regimented discipline that affected them in numerous ways. The lack of role models and mentors, insufficient money for the schools, teachers who were not trained to work with children from a different culture, as well as an unsuitable curriculum that was taught in a foreign language to them contributed to low success rates for these children. According to Loyie (2014), Dr. Egerton Ryerson, the Methodist Head of Education in Upper Canada, advised the heads of government that the education of Indians should not only consist of training the mind but also of stripping away their habits and customs of their ancestors. The schools were also cautioned not to teach the children too much for fear they would take jobs away from White people (Loyie, 2014).

Because of the poor educational achievement, many of the survivors suffered chronic unemployment or underemployment, poverty, poor housing, substance abuse, family violence, and poor health throughout their adult lives (Truth and Reconciliation Commission of Canada, 2015). These children left the school ill-prepared for the workforce, as well as unprepared to pursue the more traditional activities such as hunting and fishing. Roy Ellis, a survivor of the IRS, stated that all through his school years, he

was told he was dumb and that he would never amount to anything. He was kicked out of IRS after being there for 15 years and had nowhere to go and no skills to help him look for a job. After many years of living on the streets and turning to alcohol, he turned his life around in his early forties and got a good education. He was one of the fortunate survivors who were able to help others once he got his own life back on track (Loyie, 2014).

The residential school experience has been described as a critical factor within the cycle of trauma experienced by Indigenous people leading to the conclusion that the IRS had a profound effect that led to intergenerational trauma among the Indigenous population. Even though the Indigenous children of today did not experience the trauma firsthand of residential schools, they experienced it indirectly through the effects on their families and communities (Nagy & Schdev, 2012). The removal of children from home for long periods had lessened the chances for learning about family values, parenting, and community behavior between generations. The experiences of those that survived the IRS program deeply impacted their sense of self-worth and value as there was a systemic attempt to devalue their language and culture (Stewart & Glowatski, 2018). When children returned home and criticized the home community, they were, at worst, shunned as outsiders or, at best, left on their own as their new experiences and new language made them foreigners (Schissel & Wotherspoon, 2002). It was noted in the Truth and Reconciliation Commission of Canada report (2015) that residential schools were a systematic government-sponsored attempt to destroy Indigenous cultures and languages and to assimilate Indigenous people so that they no longer existed as distinct peoples.

The children who attended the IRS were cut off from their families, their culture, and experienced isolation and abuse while attending school. Their experiences at IRS shaped them into adulthood while preventing them from having any role models relating to their culture, as well as denying how to be a parent or how to care for someone. As the children were separated from their parents for long periods, they grew up knowing neither respect nor affection (Truth and Reconciliation Commission of Canada, 2015). These experiences of trauma, isolation, and disconnect were passed between generations. Eventually, the role of self-medicating became a means to escape these experiences and the responsibilities of being a parent. Therefore, self-medication in the form of alcohol presents significant problems for expectant mothers such as children being born with FASD, depression, stigma, anxiety, and shame from the blame they received because of their drinking (Bell et al., 2016).

Studies have shown that female students who attended the IRS were not only subjected to abuse because they were Indigenous but also because of their gender. These abuses that they encountered during their stay at the residential schools did not end when they left the school but also continued as the traumas left them with a loss of identity. Female students were targeted and discriminated against by the school officials and fellow students due to their gender, which also caused them to have difficulty entering into healthy relationships in their adulthood (Robertson, 2018). The physical abuse and rough treatment that they experienced while they attended the schools continue to haunt them throughout their lives, leading to dysfunctional adulthood. Wilk et al. (2017) posited that the trauma that they endured provided a way to conceptualize the

transgenerational effects of residential schooling, negatively impacting their lives in ways that resulted in future problems for their descendants.

According to Loyie (2014), the primary purpose of the IRS was to civilize and christianize the Indigenous children. Any traditional and cultural beliefs held by the Indigenous were belittled and said to be the work of the devil (Loyie, 2014). The methods used by the church and officials led to many children suffering from physical, sexual, psychological, and spiritual abuse. These abuses led to enduring effects such as health problems, substance abuse, suicide, trouble with the law, and dysfunctional families and communities. These schools subjected thousands of Indigenous students to horrific experiences, which contributed significantly to the present poor welfare of many Indigenous children as well as educational and economic problems (Barnes & Josefowitz, 2019). In some residential schools, 20 to 75 percent of Indigenous children did not survive. It was noted that pneumonia, influenza, tuberculosis, appendicitis, measles, physical injury, beatings, injuries from being thrown, accidents, fires, drowning, infection, freezing deaths, a fall downstairs, lack of professional medical treatment and poor overall health were among the many ways that students died (Loyie, 2014). These deaths affected the survivors in many ways, as many of the students who died were brothers, sisters, cousins, and friends.

Indigenous children who attended these schools were mocked, bullied, and abused, as well as they also had to suppress their families' cultures and traditions which helped destroy their sense of self-worth. One survivor stated that "it was a cultural genocide in which people were beaten for the language, people were beaten because ...

they followed their ways” (Truth and Reconciliation Commission of Canada, 2015). The later lives of former IRS students were varied as many progressed well as adults, establishing themselves in employment, marriage, and parenting. However, thousands experienced persistent problems that adversely affected their employment, marital relations, parenting, and societal engagement (Barnes & Josefowitz, 2019). The missed opportunity to learn Indigenous cultures, ways of life, and religious practices, along with learning their first language, had a profound impact on many Indigenous people. The transition from residential schools to home was not always smooth as there were no support systems put in place when they left the schools. The resulting social isolation, cultural trauma, and even internal racism experienced during and after leaving school caused some survivors to turn to negative coping strategies (Nagy & Schdev, 2012).

The use of alcohol and drugs resulted from the need to cope with any pain that was felt from the residential schools. The effects of the residential school system are intergenerational, with children of IRS attendees demonstrating more inferior health status than children of non-attendees, as well families in which multiple generations attended IRS have been found to have more significant distress than those in which only one generation attended (Wilk et al., 2017).

Social Stigma

Negative attitudes and stereotypes are often fed by an underlying media narrative that accentuated some of the worst aspects of current conditions experienced by many Indigenous communities, such as substance abuse, poor educational outcomes, and also the points of conflict with the government and industry priorities, such as pipeline

development, control of traditional lands (Neuman, 2016). Stigmatization, the process of negative stereotyping that can cause discrimination, remained a tremendous social challenge and a barrier to the wellbeing of marginalized populations (Aspler et al., 2018). Stigma targeted both children with FASD and the parents of children with FASD. The experience of stigma for children with FASD remained mostly unaddressed, although descriptions of general childhood experiences, especially in school, pointed to difficulties in making friends, perceptions of being different from others, and lived experiences of marginalization and oppression (Bell et al., 2016).

It has been acknowledged that stigma can undermine the prevention and intervention efforts of FASD by allocating blame, guilt, and focusing on the negative instead of the positive. Indigenous mothers who were shamed were often afraid to seek out the necessary services that they needed, therefore, preventing any interventions and support that needed to be put in place. As noted, stigma has likely been a key determinant in many of the life choices that Indigenous people made in their daily activities stemming from their psychological well-being to education, employment, housing, and life in general. The propensity to “blame the victim” often arose with Indigenous people who were accused of making poor “lifestyle” choices (Aspler et al., 2018). Coping with the stigma they felt due to the labeling, stereotyping, and discrimination took a lot of effort on their part and was often done at the preconscious level.

Stigma has been a hurdle that parents of Indigenous children with FASD and their children with FASD needed to overcome. Stigmatized individuals often felt unsure as to how they are seen or received by others and have been either too aggressive or too

shame-faced when dealing with the actions of others (Corrigan et al., 2018). The cognitive, physical, behavioral, and societal problems that they have endured and overcome negatively influenced their daily lives. Social isolation, worry, lack of knowledge, understanding, and support affected them in various ways, often having led to stigmatization, feelings of guilt, and blame. Stigma is perhaps best understood as a process that involved the endorsement by others of negative stereotypes (i.e., socially informed notions and impressions of particular groups), accompanied by prejudice, including emotion-based reactions (e.g., anger or fear), and potential discrimination (e.g., structural or personal forms of discrimination) or devaluation of persons (Link & Phelan, 2001; Corrigan & Watson, 2002; Bell et al., 2016). These Indigenous women who drank alcohol while pregnant often faced being stigmatized, promoting the effects of blame and shame felt by them. Alcohol has been considered one of the coping mechanisms numerous Indigenous mothers used, and continue to use, to help them face the trauma in their lives (Niccols et al., 2010).

FASD-related stigma has often been referred to as discrimination that is directed at substance-abusing pregnant women and their affected children throughout their lifespan. FASD is often intergenerationally linked back to the residential school experiences that have had a profound impact on many Indigenous women. Indigenous women and their children have encountered the risk of stigmatization and exclusion when a diagnosis of FASD has been made. This fear of stigmatization and exclusion has often impacted their judgment of having their child diagnosed as some Indigenous mothers felt that by disclosing this information their child and themselves might face situations that

would leave them feeling needlessly judged. Many times, people formed expectations as to whether or not most people rejected an individual with an illness, such as FASD, as a friend, employee, neighbor, or intimate partner and whether people devalued a person with this illness as less trustworthy, intelligent, and competent (Link & Phelan, 2001). Link and Phelan (2001) also stated that if one believed that others have devalued and rejected these people, one now feared that this rejection applied personally and might have wondered if others looked down on them simply because they had an illness, such as FASD, or discriminated against them because they drank while pregnant. These trust issues and stigma could have harmed all involved in the family, leading to even greater mental health problems and family dysfunction.

Stigma in the School Setting

The education system across Canada has varied from province to province. Regarding the FASD education policy that has been currently in place, it has been found to have discrepancies across the provinces. Children with FASD often found themselves without any support or interventions put in place for them. Not only did they have to contend with their disability but also the fact that many people did not understand how FASD affected them. Often teachers were not trained or well-equipped to work with students with FASD, whether they were Indigenous or non-Indigenous.

Much of the public education system in Canada has remained Eurocentric and has continued to disseminate the assimilation process started with the residential school era (Al-Suqri & Al-Kharusi, 2015). When considering the lack of knowledge that was found in the mainstream perception of Indigenous people and their lifestyles, it has been

important to consider the fact that the majority of school staff had very little training, if any training at all, in this particular field of education. Also, parents of Indigenous children with FASD often found themselves feeling stigma or discrimination as teachers did not understand or knew what to do with their child (Bell et al., 2015).

Bullying has often been encountered in the school system. It has been noted that the longer a child has been bullied, the more likely that they developed physical, emotional, and psychological effects that could last throughout their lifetime. Not understanding something often led to a child being bullied, particularly a child who was different from that person. This behavior could also be known as a microaggression, a subtle form of bullying. Microaggression has been defined as the everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether they were intentional or unintentional, which communicated hostile, derogatory, or harmful messages to target persons based solely upon their marginalized group membership (Wing Sue, 2010). An Indigenous child with FASD could be snubbed or bullied, intentionally or unintentionally, because of his disability.

Not only the children being bullied, but also the bullies could be at an increased risk of experiencing health and psychosocial problems, including depression, anxiety, substance abuse, suicide attempts, aggressive behaviors, and lower grades in school (Brownlee et al., 2014). In addition to the problem of bullying taking place at schools, a survey done by the Canadian Teachers Federation (2015) found that the greatest challenge to the teaching of Indigenous education was racial prejudice and negative stereotypes and perceptions about Indigenous peoples.

The teachers of today's Indigenous classrooms might have also encountered challenges regarding the assimilative approaches of contemporary schooling, which lacked needed cultural responsiveness in educating today's Indigenous students (O'Gorman & Pandey, 2015). Teachers have often been faced with a lack of knowledge of Indigenous culture, issues, and perspectives, which, in turn, showed a lack of awareness of the importance of teaching Indigenous education.

This could be seen when Indigenous children returned to the school system after being out "on the land" for several weeks. Being on the land brought Indigenous people closer to their culture as they became one with nature. They lived outdoors in shelters and lived off the land. Indigenous children were taught the ways of their ancestors and experienced hunting, fishing, gathering berries, and other forest products. They might be gone for days or weeks at a time. When they returned, these children might have felt being shunned or singled out because they have missed a lot of time in the classroom. Besides having a disability such as FASD, having returned to the classroom after being away for some time, could be a challenge to these children. According to the ICTI (2018), not understanding the culture of the Indigenous people and how to incorporate their culture into the education system could add to the struggle and the stigmatization felt by the Indigenous population.

Mental Health

The historical impacts of colonization and forced assimilation were viewed as the leading social determinants of health for Indigenous people in Canada, as these impacts led to intergenerational trauma, with communities struggling today against

discrimination, stigma, poverty, and social exclusion (Klingspohn, 2018). Colonization took away a significant piece of the Indigenous cultural inheritance and created many problems that are seen today. As well the residential school experience had an even more profound impact on many Indigenous women leading to mental health issues such as post-traumatic stress disorder, depression, and substance abuse, as well as a suicide rate that is five times higher than the non-Indigenous people in Canada (Klingspohn, 2018). It was noted in the study done by the Truth and Reconciliation Commission of Canada (2015) that the overall suicide rate for First Nations was twice that of the total Canadian population while the overall suicide rate for the Inuit was 6 – 11 times the rate for the general population. The intergenerational impact from the trauma of colonization experienced by Indigenous people such as residential schools, cultural prohibition, and the Sixties Scoop (apprehension of Indigenous children into residential schools and the child welfare system) intensified the risk of poor long-term mental health outcomes (Xavier et al., 2018).

Even with all the health problems that the Indigenous people faced, many did not use the mainstream healthcare services due to various reasons, such as lack of trust or remote location. Many Indigenous people felt that the healthcare services offered by Western healthcare were intimidating to them as they often experienced stereotyping and racism when they did take advantage of the healthcare found in their community. Their perception of the healthcare services could have overwhelmed them in such a way that they would see them not taking advantage of these essential services and avoiding the care they required. Numerous reasons why Indigenous people expressed reluctance to

engage with mainstream healthcare services included racism, “being treated as a second-class citizen,” and lack of Indigenous staff and cultural practices, along with judgmental attitudes (Hadjipavlou et al., 2018). When healthcare workers made assumptions about the situation, discrimination and racism were felt by the Indigenous population resulting in poor health as stigma and discrimination remained a major hurdle when accessing mental health services.

Boska et al. (2015) stated that a significant challenge to achieving mental wellness for many Indigenous people was a general lack of appropriate and engaging mental health services. The current mental illness service delivery model had strong psychiatric and biomedical traditions and focused mainly on individualized interventions as opposed to a more holistic, Indigenous model of wellness that involved the physical, emotional, spiritual, and mental aspects of a person who was always in connection with his or her community, family, and the natural environment (Firestone et al., 2015).

The impact that was felt by the residential school survivors has played a major role in the mental health of many Indigenous people. Early life exposure in loss, adversity, and maltreatment/trauma increased lifetime risk for serious mental health disorders and alcohol/drug abuse (Barnes & Josefowitz, 2019). These life experiences could have significantly disrupted personal life, family relationships, education, and employment. It has been shown that residential schools could be linked to many risk factors for poor pregnancy outcomes among Indigenous women who abused alcohol, poor health, low levels of education, and chronic poverty. The substance abuse that stemmed from the intergenerational trauma of residential schools has been linked to

mental health problems and family dysfunction that has often been found in the various Indigenous communities. These two factors, mental health and substance use, have been identified as health priorities currently facing Indigenous peoples in Canada (Firestone et al., 2015).

MacIntosh (2017) stated that the Mental Health Commission of Canada traced the cultural disruptions caused by the Indian Residential Schools and the historic child welfare system “to high rates of mental health problems, addictions and suicide among First Nations, Inuit, and Metis linked with complex problems such as family violence and involvement in the criminal justice and child welfare systems. “ Mental health disparities between Indigenous and non-Indigenous people in Canada were related to underlying economic, social, and political inequities that were legacies of colonization and the oppression of Indigenous cultures – now recognized as “cultural genocide” by the Truth and Reconciliation Commission of Canada (Hadjipavlou et al., 2018).

Economics

The societal burden for FASD has been immense due to the lost productivity, excess medical, and educational expenses and costs to the foster care system and the criminal justice system (Banerji & Shah, 2017). Many Indigenous people were traumatized by their residential school experiences and turned to alcohol or drugs. They then found themselves among the disproportionate number of Indigenous populations who came into conflict with the law. A link has been found between substance abuse of residential school survivors and the over-incarceration of Indigenous people (Truth and Reconciliation Commission of Canada, 2015).

The studies that have been done thus far on the economic costs associated with FASD all reached the same conclusion; the costs were very high. Miller et al. (2014) stated that a recent Canadian study evaluated the cost of FASD from birth to 53 years to be \$24,041 per individual for each year, translating to an annual total Canadian cost of \$5.3 billion, which included direct costs (e.g., medical, education, social services, out of pocket) and indirect costs, such as productivity losses.

Lower educational attainment for the children of Survivors has severely limited their employment and earning potential, as well as those of their parents (Truth and Reconciliation Commission of Canada, 2015a). The income gap was considerably lower between the Indigenous and non-Indigenous. There have been several factors which have contributed to poorer economic outcomes for Indigenous people. Some of these factors included lower educational attainment, the remoteness of the location, insufficient training, lone parenthood, and discrimination. Since 2006, Indigenous people in Canada have made some gains, but there has remained a significant gap between Indigenous and non-Indigenous populations (National Aboriginal Economic Development Board, 2015).

The high incarceration rate of Indigenous people which many saw as an outcome of colonialism and residential schools, combined with the typical stereotypes of the “drunken Indian” might have led one to assume that FASD was a major contributing factor to Indigenous peoples’ over-involvement with the criminal justice system (Bracken, 2008). Often FASD offenders might have admitted to things that they did not do and pleaded guilty without understanding the implications of this plea. The connection of incarcerated Indigenous people could be made to discrimination and broader health

and social development issues, including FASD (Bracken, 2008). FASD and the criminal justice system were often seen as going hand in hand and uniquely an “Indigenous” problem. FASD and the criminal justice system in Canada must take account of two major issues: the continuing over-representation of Indigenous persons in the criminal justice system, as well as the impact of three centuries of colonial policies toward Indigenous persons, and in particular the legacy of discrimination, forced assimilation (mostly through the Residential School system) and economic marginalization (Bracken, 2008).

Summary and Conclusion

Dej (2011) stated that rarely were the experiences of parents/caregivers caring for an Indigenous child with FASD researched except for those children who have been adopted by white parents. The stigma that many Indigenous parents have faced could be one reason why their story was not heard. People with FASD have reported problems such as social exclusion, weak support systems, and employment discrimination (Aspler et al., 2018). Most often the common viewpoint among parents of a child with FASD was that the understanding and support needed was still missing.

Colonization and intergenerational trauma were the roots of many of the challenges that Indigenous adults with FASD have contended with; to understand the effect of FASD in Indigenous people, the implication and impact of colonialism must first be understood (Samaroden, 2018). This chapter focused on the historical groundwork of the current situation that Indigenous people must surpass and created the foundation to address the current gap related to educational stigma. The following

chapter looked at an overview of the proposed methods for studying the topic of interest, educational stigmatization of parents of Indigenous school-aged children with FASD. A review of the research design and the method to be implicated in the study is discussed.

Chapter 3: Research Method

Introduction

The purpose of this chapter is to introduce the research methodology for this narrative inquiry, which focuses on the educational stigma of parents of Indigenous children with FASD. This approach allowed for a deeper understanding of how educational stigma has affected parents of Indigenous children with FASD and provided a way to showcase the data collected that coincided with this phenomenon. This chapter focuses on the research method, includes an overview of the methodology, participants, procedures, and analysis method, and concludes with a discussion of trustworthiness, validity, and ethical procedures.

Research Design and Rationale

This study focused on the following research question to explore the perceptions that parents of Indigenous school-aged children with FASD have of their experience with school personnel and examine if those perceptions of their experience included stigmatization.

RQ: How do parents of Indigenous school-aged children with FASD describe their experience with school personnel?

This phenomenon was addressed by using a narrative inquiry approach.

According to Creswell (2014), narrative research is a qualitative strategy in which the researcher studies the lives of individuals and asks one or more individuals to provide stories about their lives. According to Creswell (2006), narrative research can be defined as a study of experiences as expressed in lived and told story of individuals. Creswell also

stated that this information is then often retold or restored by the researcher into a narrative chronology.

It is important to note that as individuals are telling their stories, they are not isolated and independent of their context. Rather, narratives capture both the individual and the context (Moen, 2006). Moen (2006) also stated that storytelling is a natural way of recounting experience, a practical solution to a fundamental problem in life, creating reasonable order out of experience. The knowledge that was gained from this qualitative research informed, supported, and contributed to the understanding of the educational stigma parents of Indigenous children with FASD encounter in their daily life. A qualitative method was used to answer questions about experiences, meaning, and perspective, and it captured expressive information about the beliefs, values, feelings, and motivations that underlie the behaviors (Berkwits & Inui, 1998).

Yang (2011) has stated that narrative is the story of life history and that humans as storytelling organisms live not only individual storied lives but also social storied lives. This qualitative approach is appropriate to use when one is looking for specific details. These details can be used to understand the perspectives of the participants, explore the meaning that they give to the phenomena, or observe the process in more depth (Brikci & Green, 2007).

Narrative inquiry allows the researcher and readers to enter into the experiences of others and serves as a starting point for understanding and interpretation (Yang, 2011). I planned on gaining a more thorough understanding of the educational stigma that parents of Indigenous children with FASD face through the use of a narrative inquiry

approach as it gives me a better sense of their situation by hearing about their experiences firsthand. For my narrative study, I focused on parents of Indigenous children with FASD while I addressed the phenomenon of the educational stigma that they encountered. Merriam (2001) suggested that the insight derived from narrative studies can directly influence policy, procedures, and future research.

Role of the Researcher

The role of the researcher for a narrative study, according to Unluer (2012), has the following three characteristics:

- a good understanding of the culture being studied,
- the ability to not alter the flow of social interaction unnaturally,
- potentially an established relationship that promotes both the telling and judging of the truth.

For this study, I was responsible for obtaining the proper documents and permission forms from the Walden Institutional Review Board (IRB) and the participants who took part. I was also responsible for finding and contacting the participants, interviewing, analyzing, and interpreting the data, and writing a summary of the findings. I have worked in the educational field for the past 40 years, with the last 10 plus years working with students with learning disabilities. No participants who took part in this study had a direct relationship to me that would represent a conflict of interest creating any bias in the research study.

Qualitative Methodology

Population and Sampling

The samples used in qualitative research are usually purposive, meaning that they are selected because of the useful data that can be generated from them for a study (Brikci & Green, 2007). The participants that were used in this study were parents of Indigenous children with FASD. These parents came from various Indigenous communities in Northern Canada.

Snowballing was an effective means of recruiting as it allowed me to recruit participants through other contacts. This type of sampling is often used to find and recruit “hidden populations,” that is, groups that are not easily accessible to researchers through other sampling strategies (Mack et al., 2005). The participant sampling pool was limited to those participants solicited for this research, as outlined in the criteria set out in the study.

Inclusion and Exclusion Criteria

The criteria for the participants are as follows:

- Parents, aged 18 years and older, of Indigenous children with FASD
- Able to speak English
- Able to access the internet or other means of communication, as necessary

Instrumentation

Developing the proper instrument tool for data collection process was crucial. Once the research design had been determined for my study, I developed an open-ended semi-structured interview instrument to gather the data that addressed my research

question. I used interviews to collecting my data regarding the experiences of parents of Indigenous school-aged children with FASD with school personnel. The interview instrument consisted of eight to 10 questions, as well as follow-up questions that further clarified their responses. An expert panel reviewed the interview instrument for consistency with the research questions.

Interviews can resemble everyday conversations, but to establish reliability and validity, they must be structured in a more rigorous way than an everyday conversation. In-depth interviews are the most common form of data collecting for narrative studies. They are optimal for collecting data on an individual's personal history, perspectives, and experiences, particularly when sensitive topics are being explored (Mack et al., 2005).

Interviews allow for more spontaneity and interaction between the researcher and the participant. Using open-ended questions and probing, I gave participants a greater opportunity to respond in their own words, allowing them to elaborate and add more to their story (Mack et al., 2005). The flexibility this provided to the interviewer and interviewee was invaluable. While I interviewed my participants, I listened to and read their responses very carefully. This engagement helped me probe or asking follow-up questions that stemmed from their responses. These open-ended questions evoked responses that were meaningful and salient to the participant while being rich and explanatory (Mack et al., 2005).

I used an interview guide (Appendix A) to help me with a list of questions that I wished to ask the participants, along with some probes and follow-up questions that helped the interviewee expand on their responses. It was imperative to develop the right

questions to ask and to remember that the respondents are sharing their perspective on the issue at hand, not my viewpoint (Brikci & Green, 2007).

Procedures for Pilot Study

Qualitative interviews offer rich and detailed information for understanding people's experiences; however, qualitative inquiry might be difficult for inexperienced researchers to adequately perform the interview (Majid et al., 2017). By conducting a pilot study of the interview process, I was able to improve my interviewing style, as well as check for any ambiguities in the interview questions. It was an integral aspect of the process of conducting qualitative research as it highlighted the improvisation of the major study (Majid et al., 2017). I piloted the interview instrument with two participants from the Indigenous community who were familiar with FASD. There was no compensation given for this pilot study.

Procedures for Recruitment, Participation, and Data Collection

The participants were recruited through my existing professional network, such as school boards, tribal band offices, and Indigenous colleagues. Flyers (Appendix B), as well as word of mouth, were used to help recruit participants for the study. Snowballing, as stated above, was used to assist in the recruitment of participants. A signed informed consent form was required for each participant before participating. I had looked at approximately one or more participants for my study. The participants were told that they could withdraw at any time during the study. Participation in the study was voluntary, and there was a \$10.00 gift card given as a thank you for participating.

Once I contacted the participants, I explained the purpose of my study and how I would be conducting the data collection. The participants were asked to take part in an interview-style format, which will be done by e-mail, telephone, video conferencing, or face-to-face. They were asked to respond to open-ended questions (see Appendix A) regarding possible educational stigma that they may have had experienced. With open-ended questions, the participants were free to respond in their own words, describing their experiences with more complexity than “yes” or “no” answers (Mack et al., 2006). All information about the study, which included how the data were collected, stored, and transcribed, was disclosed to the participants for complete transparency. Any questions or concerns from the participants were answered at the start of the study, as well as throughout the study. Confidentiality and anonymity are vital while conducting your research study.

As stated previously, I interviewed the participants by e-mail, telephone, video conferencing, or face-to-face. The participants were made aware of the fact that I would be audiotaping the interview in addition to taking notes throughout the interview. Taking notes while listening to their responses allowed me to probe deeper and to have other follow-up questions that helped them elaborate on their responses. To establish the anonymity of the participants, they were given pseudonyms to protect their identity.

At the start of each interview, I ensured that the consent of the interviewee was in place to proceed with the interview and clarified any issues of anonymity and confidentiality. Secondly, I reminded the participants of the purpose of the study, the approximate amount of time needed for the interview, the procedures that had taken place

in the study, and their right to withdraw from the study at any time. Each interview was approximately 60 to 90 minutes in length. Once the interview was completed, I let the participant know the process of data analysis as well as when they would receive a copy of the analysis to verify the accuracy of the transcription. The data were transcribed verbatim by hand as well as by using a transcription service. The audiotapes and transcripts have been stored in a locked filing cabinet to ensure confidentiality.

Qualitative Data Analysis Plan

Organizing the data in a rigorous, standardized way was essential for the security and the validity of the study results (Mack et al., 2005). It was crucial to ensure that the analysis of the data was reliable and its validity was safeguarded. This part of the study, the analysis of the data, has often been seen as the most challenging part. To ensure the reliability of the analysis, I needed to keep meticulous records of all the interviews and notetaking, as well as document the process that the analysis went through in detail (Hancock & Algozzine, 2006).

Preparing the data for analysis required transcribing all the data and typing up the transcriptions. The transcription of notes began as soon as the first interview was over. To transcribe the data, I listened carefully to the interview and wrote down everything that is said. By transcribing every word that I heard, it ensured the accuracy of the transcription. The notes that I took during the interview were also written up to accompany the transcription.

Centralizing the data is a key element of managing data in an organized and systematic manner (Mack et al., 2005). The data from my study is kept in a locked filing

cabinet in a secure place. All the data was organized and identified according to the pseudonyms assigned to the interviewee and put in sequential order of the date of the interview.

A thematic analysis was used to look at the data, identifying the common themes that emerged from it. These initial themes formed the basis of the coding scheme that was used. Hancock and Algozzine (2006) stated that it is useful to begin the coding scheme as soon as the initial data has been collected. Once all the data has been coded, I arranged the codes into categories. The patterns and relationships that emerged from the themes were the basis of my findings.

The interpretation of the data analysis was summarized and compared for similarities and differences in the participant's accounts of their experiences. Creswell (2014) recognized that a researcher's background played an integral part in the meaning-making process of the analysis. During the interpretation stage of the analysis, I drew from my educational experience to support the understanding of their experiences. I attempted to identify themes or categories of the experiences that they have endured. The themes that came out of this study further enhanced their experiences and helped support other families that have been going through the same experience.

Issues of Trustworthiness

Trustworthiness

The trustworthiness and validity of qualitative research has depended on what the researcher saw and heard. Establishment of validity is one of the strengths of qualitative research and is based on determining whether the findings are accurate from the

standpoint of the researcher, participant, or the readers of the account (Creswell, 2014).

The most important aspect of establishing trustworthiness is credibility.

Credibility

Creswell (2014) stated that there are eight strategies for ensuring the credibility of the research: triangulation, member checking, rich, thick description, clarification of bias, presentation of discrepant information that runs counter to the themes, prolonged time in the field, peer debriefing, and external auditor.

Triangulation of data was used through the interview transcripts, as well as member checking. Member checking has allowed me to take the transcripts back to the participants to verify the accuracy of their interview. This opportunity gave them the chance to read the interpretation of the data for accuracy, as well as expand, add, or delete any information that they felt was relevant to the study.

Transferability

I established transferability by providing evidence that the findings from the case study can be transferred to other contexts. According to Ravitch and Carl (2016), transferability can be achieved by having a rich, thick description of the data so that the reader can make comparisons to other contexts based on the information provided.

Dependability

Dependability was the stability of the data provided. It shows that you are using the most appropriate method to answer your research question. Dependability can be achieved by using triangulation and by confirming that the most appropriate data

collection method was used. A solid research design is key to dependability (Ravitch & Carl, 2016).

Confirmability

Confirmability related to the fact that the research findings are shaped by the participants and not by the researcher (Ravitch & Carl, 2016). To do this, I provided details of the process used for data collection, data analysis, and interpretation of the data. I also explained the decisions made in the research process, such as the rationale for the coding and themes that were used. It is important for other researchers to be able to replicate the results to show that those results are a product of independent research methods and not of conscious or unconscious bias (Devault, 2019).

Intra and Intercoder Reliability

In addition to the triangulation of data and member checking, I also had a peer review of my interpretation of the data to review my findings and interpretations. The peer reviewer was another Walden University student who is also in the Ph.D. program and is familiar with the rigors of doctoral research. Having a second coder has allowed for crosschecking of the coding and interpretation of data. Once the peer reviewer had completed their review, a conference call or face-to-face meeting was held to discuss the research study. Notes were taken from the conference call, and any revisions to be made was done as appropriate. The notes from the conference call or face-to-face meeting are kept and stored with the research data collected.

Ethical Procedures

Treatment of Human Participants

I provided the participants chosen for this study with an informed consent form (see Appendix B) outlining the purpose of the study, voluntary nature of the research, benefits, and risks of the research, list of requirements for participation, as well as contact information if the participants required additional information. All information and data collection has been kept in strict confidence. The participants were informed of the confidentiality and anonymity of their participation. The participants were given pseudonyms so that their identity was kept confidential. The participants were also told that they have the right to withdraw from the study at any time during the process.

Treatment of Data

All data collected and analyzed has been stored in a locked filing cabinet and stored in a secure location. Confidentiality is key and all data including audio transcripts will be stored for seven years, at which time it will be destroyed according to APA standards.

Threats to Validity

I minimized any threats to validity by piloting the interview instrument to ensure that the interview questions aligned with the research questions in addition to improving my interviewing skills. I also had the dissertation committee members and an expert panel review my interview instrument, confirming the alignment and clarity of the interview questions.

Summary

This narrative study involved one or more participants who lived in an Indigenous community and have experienced educational stigma relating to their child who has FASD. Chapter 3 outlined the purpose of the study, research design, and rationale, the methodology used in the study, the instrument used, data collection method and analysis, along with the issues of trustworthiness. Chapter 4 includes a presentation of the findings of the study with the results of the study and the implications for future research being presented in Chapter 5.

Chapter 4: Results

Introduction

The purpose of this study was to explore the perceptions that parents of Indigenous school-aged children with FASD have of their experiences with school personnel as well as to examine if these perceptions included stigmatization. This chapter focuses on the presentation of the data collected and the interpretation of themes which attempted to answer the research question. The themes which emerged from the interview of self-completed questions are discussed in this chapter. The research question which guided the interview questions was:

RQ: How do parents of Indigenous school-aged children with FASD describe their experience with school personnel?

To address the gap found in the literature review, I used a narrative inquiry design to collect the data from the participants. By sharing their stories through the interview questions, I was able to gain valuable insight into their experiences. During the entire process of recruiting and interviewing the participants, I kept a journal reflecting my thoughts and understanding of the process. Writing in the journal allowed me to jot down further questions that could be used to follow up on and explore deeper their responses. This chapter is organized into sections that describe the pilot study, research setting, participant demographics, data collection, data analysis, and evidence of trustworthiness and results.

Pilot Study

A pilot study was conducted prior to implementing the research of my main study. This pilot study allowed me to improve my interviewing style, as well as ensure that the questions I asked aligned with the research question and that there were no ambiguities. Prior to the pilot study, the interview questions were sent to an expert panel that was made up of various professors from Walden University who are experts in qualitative research. The questions were sent back to me for further clarification and accuracy before they were included in the IRB application for approval.

Participants were recruited for the pilot study through the posting of flyers, as well as by the use of snowballing. Originally two participants were to take part in the pilot study, but at the last moment, one of the participants declined to take part stating that the study was not a good fit for her. The one who did participate was non-Indigenous whom had adopted an Indigenous child with FASD. The participant was given the consent form for permission along with information on the study prior to being interviewed. Any questions the participant had were answered before the interview took place. The information collected from the participant was very detailed and informative. This participant had adopted three children; two were Indigenous and the other child was Korean. One of her children was diagnosed with FASD, but she suspected that the other child was also FASD as he met the criteria. Due to the history of the birth mother not being available, a diagnosis was not made for her second child.

The interview was held using the platform Zoom and was recorded using the record feature on Zoom as well as a digital recorder as a back-up. Notes were also taken

during the interview to help facilitate follow-up questions and add to the information given. After the interview was completed, the recording was transcribed, and the transcription was made available to the participant for accuracy. Creswell (2014) stated that taking the information to the participants allows the researcher to conduct a follow-up and provides an opportunity for the participant to comment on the transcripts for accuracy. The transcript was read and color coded according to the patterns and themes, and repetitive words were underlined in response to the interview questions.

The pilot study prepared me for the main study by allowing me to experience what I would encounter while conducting the main study. The pilot study also showed that none of the interview questions needed to be changed moving forward.

Research Setting

The research study took place in various communities in Canada, in particular Northern, Southern, and Western Canada (see Table 1 below). The participants were interviewed either face-to-face via Zoom, by telephone in their home setting, or by email. Social media posts, flyers, and snowballing were used to recruit participants. The participants included foster and adoptive parents of Indigenous children with FASD. Each of the participants received information on the research study, consent form, and the interview questions. The participants were given alpha-numeric identifiers to ensure confidentiality. All documents were retained and stored in a secure filing cabinet.

Demographics

The study consisted of six participants from various parts of Canada. Each of the participants identified themselves as being either a foster or adoptive parent of an

Indigenous school-aged child with FASD. Table 1 represents the demographics of the participants.

Table 1

Main Study Demographics

Participants	Study	Area of participation	Parental custody
P 1	Main	Western Canada	Foster parent
P 2	Main	Western Canada	Foster parent
P 3	Main	Western Canada	Foster parent
P 4	Main	Southern Canada	Adoptive parent
P 5	Main	Northern Canada	Adoptive parent
P6	Main	Northern Canada	Adoptive parent

Data Collection

I received IRB approval, # 04-05-20-0354660, in April 2020 and completed my data collection in February 2021 once saturation was achieved. According to Flick (2018), saturation refers to the point in data collection where data become repetitive and do not move in a new direction or raise any new questions. After reviewing the completed transcripts, I noted that saturation was evident for this study.

The research began with a pilot study to establish the data collection instrument's validity. Once this was completed, the full study was implemented. The main study was completed through Zoom, telephone, and email interviews. The length of time from the

initial email of the interview questions until completion was approximately 2 weeks, while the Zoom or telephone interviews took approximately 60 to 90 minutes.

After completion of the interview, the participants were debriefed on the interview to address any concerns or questions they might have had. According to McMahon and Winch (2018), debriefing sparks immediate reflection on emerging findings. Through the debrief, the participants can add any additional comments and clarify comments that were made. Through systematic debriefing, researchers can identify and address gaps in the data, capture nuances and other non-verbal information, enhance intellectual partnership within teams, triangulate data, and build theory (McMahon & Winch, 2018).

The data collection stage was a difficult process due to the difficulty in recruiting participants for the study. The recruitment process took approximately 10 months. The process seemed smooth when I started the pilot study, but I was met with a number of roadblocks due to the Coronavirus pandemic taking place, and many communities were on lockdown. People tended to stay home more and were not out and about to see flyers. It was also difficult to post flyers in the communities as many places were either closed or limited what was allowed to be put on bulletin boards. Other recruiting methods were put in place, such as snowballing and reaching out to community groups involved with individuals with FASD and other groups that could assist in supporting the recruiting process.

While recruiting participants, I reached out to a former colleague and asked her if she would post my flyer in her community or send my flyer out to her contacts. She asked

me “if there were no non-Indigenous people with children with FASD.” I did explain to her that my study was on Indigenous children and not non-Indigenous children; therefore, I was just looking at Indigenous children at the moment. She then went on to say that she would not feel comfortable giving me her aunts or cousins or friends’ names who might have had a hand in being the reason their kids suffer now for their darkest time in their lives. She said that she was “Sorry but would not take part in my study as it was a hard topic and when her people were just starting to try to heal that being part of this would bring guilt and anger.” Kilian et al. (2019) noted that there is commonly a sense of apprehension and mistrust among Indigenous communities towards research being done by non-Indigenous researchers. After talking to her, I wondered if that was the case here along with the feelings of guilt and shame that may be brought up during the interview.

These comments made by her resounded with me as I continued to find it more difficult to find birth mothers of Indigenous children with FASD to participate in my study. I was able to recruit foster and adoptive parents of Indigenous children with FASD, and this made her points much clearer to me. Bell (2015) stated that large knowledge gaps limit our understanding of how labels or public attitudes that are enacted through prejudice and discrimination impact the experiences of children with FASD and their parents or caregivers.

As stated previously, I met a number of roadblocks from the start of my data collection. During the stage of data collection, I made several applications to IRB for changes to my study. My study originally started as a case study, but due to various obstacles during the process, I changed my method to a narrative study. The idea of

narrative inquiry is that stories are collected as a means of understanding experience as lived and told, through both research and literature (Savin-Baden & Van Niekerk, 2007). This approach focuses on the use of stories as data. Storytelling, in its various forms, has long been championed as a rich tool for justice-seeking, truth-telling, and Indigenous self-determination (Caxaj, 2015). With this in mind, using the narrative approach seemed to be the best method for my research.

I had originally started to look at only Indigenous parents of children with FASD, but because of the difficulty of finding participants, I contacted IRB to have non-Indigenous parents/guardians of Indigenous children with FASD included in my study. Once that approval was made, I found that it was a bit easier to find participants for my study. I originally thought I would use participants from all over Canada. I contacted the Canadian government to discuss procedures to do research on Indigenous people and to inquire if any special requests had to be made. After speaking with the representative about my research, I was told that there were no specific requests to be made. A few months into my search for participants, I was told that if I wanted to use any participants from the Northwest Territories, I had to send in a request to the Aurora Research Institute for permission. After discussing it with the Institute and my chair, I decided to exclude participants from the Northwest Territories due to time restraints. I then concentrated my search for participants from other areas of Canada.

Including non-Indigenous parents who either fostered or adopted Indigenous children with FASD opened up another avenue to include in my research. This was backed up with a statement made by a colleague, as well as one parent who felt that many

Indigenous parents felt guilt or shame because their child has been diagnosed with FASD and often will not participate in studies like this as they do not want to talk about this topic. She went on to say that they would much rather ignore or “sweep it under the rug” instead of face what had happened. She attends parents’ groups for children with FASD and has found that many of the parents are non-Indigenous in her group as the Indigenous parents feel that by attending these support groups they are admitting that they drank during their pregnancy and are the reason why their child has FASD. These comments resonated with me and showed how the need for more research is needed in this area.

Throughout the duration of the interviews, I took notes, which included my thoughts, interpretations, and reflections on the data being collected. The discipline of journaling in qualitative research helps to ensure the rigor of the research process as well as the trustworthiness and authenticity (DeCarlo, 2018). The interviews were recorded using a digital voice recorder, and the Zoom interviews were recorded using the audio recording feature within the platform. All the participants who took part in the Zoom or telephone call interview consented to being recorded so that a more accurate transcript could be delivered.

The participants selected times that were the most convenient for them; therefore, the interviews took place at various times throughout the process. I encouraged the participants to share as much information as possible for each question. I also told them if any question made them uncomfortable or they did not want to answer a certain question that they were free to skip over the question. The open-ended semi-structured interview questions allowed each participant to elaborate and answer the questions in a narrative

style. Throughout the interviews, I took notes and asked them further questions so that they could add detail to the information that they had already provided for me. The participants provided me with a wealth of knowledge and stories that they wished to share about their experiences. One participant informed me that she wanted everyone to know how to support their child and ensure that they are getting the education that they deserve.

At the end of each interview, I thanked the participants and informed them that I would send them a copy of the interview notes once they were transcribed. I also sent them a Visa gift card as a thank you for their time and participation. I reminded the participants that their identity and participation in the study would remain anonymous and confidential. Each participant was given a number to coincide with their interview.

Following each interview, the notes were transcribed and securely saved in a password-protected account using a speech to text platform called Rev. The transcripts that I received from Rev were reviewed and compared with the audio recordings and notes to clarify the participants' responses and to add anything that may have been missed by the recording software platform. The transcripts were sent to each participant that requested to view them, and no changes were made to the transcripts once they were reviewed. Many of the participants were excited about the study and thought that it was a good avenue to get their thoughts, experiences, and ideas out to more people.

Data Analysis

Stories often help shape us, in particular when relating major life events that has happened to us. The tales we tell hold powerful sway over our memories, behaviors, and

even identities (Dingfelder, 2011). By having parents relate their stories of events that happened to them through the use of semi-structured, open-ended questions it allows them to hone in on their personal experiences.

Once the data collection process is completed, the information gathered needs to be organized and analyzed. According to O'Connor and Gibson (2003) the analysis of data collected from qualitative interviews can be defined in the following steps: organize the data; find and organize the ideas and concepts; build overarching themes in the data; ensure reliability and validity in the data analysis and in the findings; and complete an overview of the final results. After the interview process is completed, the data can be organized, transcribed and reviewed. By listening to the audio recordings of the interviews and reviewing the written transcripts, I was able to dive deeper into the understanding of what has been gathered.

Rubin and Rubin (2011) state that the use of a formal system in data analysis should be used in order for researchers to get at the meaning of their data much easier. This system involves the following: coding techniques for finding and marking the underlying ideas in the data; grouping similar kinds of information together in categories; and relating different ideas and themes to one another (Rubin & Rubin, 2011). While reading the data, I color-coded statements that I felt belonged together by underlining words or statements that were similar. From there, I developed a word document table in which I condensed the responses given to me by the participants according to the questions asked.

Once I had categorized my responses according to the questions, I then looked at the ideas and themes that emerged from the data. By looking at the responses from each specific question, a list was made of specific words or ideas that continuously came up. Many events, themes, and meanings can come out of a story and it is important to pay close attention to them and their meanings (O'Connor & Gibson, 2003).

I created a secondary data table that identified the words and ideas used frequently in their responses and added another column that helped organize these ideas into codes or categories. The third data table that was completed consisted of organizing the codes or categories into themes. I initially narrowed down the categories into ten themes and from there, I was able to delve deeper into the themes. The ten themes were shortened into five themes with sub-themes included within them. The themes that resulted from the coding were: impact of bullying; warning signs and consequences of actions; bias and racism; contradictions of parents; and supports, resources, and recommendations.

Evidence of Trustworthiness

Audio recordings were used for every face-to-face interview and these audio recordings were then transcribed. The participants were given the opportunity to review the written transcripts to clarify the responses given by them during the interview. No changes were made to the written transcripts. Member checking occurs when researchers ask the participants to review the data collected which helps establish credibility and validates trustworthiness (Devault, 2019).

Study Results

This study addressed the experiences that parents of Indigenous children with FASD had with school personnel. Five themes emerged from an exhaustive review of the transcribed interviews. These themes identified five areas that supported the stories given by all six participants and aligned with the research question that guided the study.

Theme 1: Impact of Bullying

The first thing that emerged from the research question focused on bullying. All six participants, P1 through P6, responded with the common theme that bullying impacted them in some form.

The subthemes of bullying were related to shunning, apathetic and negative feelings, indifference, avoidance, dismissal, as well as detachedness and lack of interest or concern. When asked “How did the other children at school act towards your child?” as well as “Has your child experienced any bullying from other children at school?”, all six parents stated that overall, there was some form of bullying going on at school which often overlapped outside the school.

P2 said that “Yes one child reported to me of some peers being mean not including her in activities or with older children who teased her.” This in turn would make her daughter become even angrier and often would then not be nice to them. P2 remembers how upset she was at what happened to her daughter. She would be excluded from birthday parties and other activities in the class. She said, “the students would make fun of her, would cry and scream just like she did in class at times (mimicking her),”

P1 mentioned that her child would often cry when telling what happened to her. This was a vicious circle which often led to her daughter being excluded from many activities as well as being removed from the bus and not allowed to go back on it.

Yes, there were times she would cry and share what students had done to her. She was also not so nice to many students, either at times. She is skilled at manipulation on many levels with children her age up to adults. She was always blaming her problems on outside sources; she was never the initiator in her mind. A lot of time was spent at school addressing many issues between herself and other students with the teacher, educational assistant, and principal to help bring a positive light to the situation. She was removed from the bus because of what was happening.

Size can often be an issue and P5 mentioned that her son was quite big for his age. He did not know how to handle the situation at school and there did not seem to be any support given to him. Many of the children feared him.

It was brought up, saying ... They never talked about it being his size, but they did talk about that kids are afraid of him. A lot of kids are afraid of him. He was also very angry, right? They tended to run away from him and call him names. They felt threatened by him and considered him to be a bully.

Many of the things that the daughter of P6 did bordered on inappropriate actions linked with intimidation and frustration. The other girls at her school felt threatened by her and were often mean to her. She did not understand why they acted that way to her and would retaliate by swearing at them or wanting to pick a fight. P6 stated that her

daughter was bullied both at school and online. Inappropriate comments were made about her heightened sexuality, but she did not understand that the other students were teasing her and calling her names. P6 commented that:

Her social skills are really low, and so she just. She doesn't get many opportunities to be able to forge any kind of friendships, and when she does, she doesn't know what to do with them, so they don't end up going anywhere, so she feels very isolated. She feels alone. She watches all these girls hang out in groups, and nobody wants to hang out with her. The boys just want nothing to do with her, or sex, and the teachers don't understand her. Some of the girls find her threatening towards their boyfriends, because she's putting herself out there to their boyfriends and she doesn't see those boundaries, those natural social boundaries. Yeah, so they get upset with her and they start fighting with her and calling her names and bullying her online. Then, she's also very low impulse, right, and she's very reactive. She doesn't understand sometimes, too. A girl will say, "I don't like that, that's not very kind." She'll be like, just start swearing and calling her names, and she's like, "I fucking hate you too, why does everybody hate me?" Then she's like, "Do you want to fight?" It's like, the girl was just politely telling her-

The bullying tactics did not just stop with the students. In answering the question, "Tell me about any incidents of blame or stressful events that you may have experience with school personnel", P4 mentioned that her son was bullied by his teacher.

It was fine until grade five, and then that teacher didn't know how to deal with him, and she put him in the corner, and he basically didn't do anything at all. He didn't talk to anyone, and he didn't even interact with anyone. He had shut down. We went in to say, "What is going on?" Then we realized he's sitting in the corner, facing the wall, by himself and he had all this work in his desk, that's stuff he couldn't do at all, and so we pulled him from the school that day, let's say, I gave heck to the teacher and the principal and they really don't care but that's okay. I felt better when I did that, because then our son knew that we weren't okay with it. Her son was in the class too, and she was mad because her son the year before had been picking on our son, and then I think she got told she would have to move her son. That she wasn't going to be the teacher. So, she was mad. When they moved to the reservation in their area, P4 mentioned that the students would run away from him as they didn't know how to take him. She said:

Some of the kids didn't understand him at that school, especially when he was younger, because he's just so impulsive. He just doesn't think about things when he does them. He liked to hug them and as he grew older and bigger, the children felt uncomfortable and called him names when he went near them. His lack of understanding why they ran from him made him feel very alone. So at first it was more rough because people didn't understand him. They didn't understand why he was like touching them or bugging at them or trying to it's because he didn't know how to interact and joke with them. And so he was doing things that were younger. So people were like, what are you doing? Kind of thing. But yeah. So

that was more difficult. But now it's like everybody knows. And there's been the riot act, read to at least one class last year for bullying.

P3 talked about a few incidents in which her daughter was more the bully than the other children.

She was not nice to them so they in turn, would be mean to her. When this happened, she would then burst in to tears and say no one loves me. She did not understand why they were mean to them as well as understand why they excluded her from some things. She would often consider herself to be the victim and the other children are bullying her.

P3 mentioned that her daughter lied a lot about things that she has done saying that they always picked on her first and she got all the blame. P3 stated that:

If she did things, they would blame her for it. Like she drew pictures of her teacher with a noose around his neck and hanging off the whatever gadgets she made. She made those kinds of pictures in his class time and they were taken to the office and dealt with. Yeah, she would have to be confronted with things she did but they would blame her for things she hadn't done. I remember a time when she was a little girl maybe six, seven years old, I'm not sure she loved the playground and she was bullied, but generally speaking, it has been very little, very little bit of bullying. Although on days that she was not in a good mood, she would classify anything or just outright say, you know, I'm being bullied. Nobody loves me, but that's such a common thing always to say, nobody loves me and, and it's not true. So she would exaggerate all the time. So when she said, "I'm

being bullied," I needed to get the information and find out it wasn't. In fact, it was the other way around. She would be bullying. Especially by taking things. Like if they had a nice purse, or a pair of pants, or a hoodie, or a water bottle, or a necklace, or whatever, somehow, she managed to take those things home by bullying them or manipulating them. She did a lot of manipulating. Then when I saw these things at home, it was always, "Oh, so-and-so gave this to me," and I'd have to call their parents and find out it wasn't really the case. Or sometimes they would say, "Well, she just really, really pleaded to have it and made all kinds of deals to have it," and then they had consented. So she had a way of really getting her way with things.

Many times they had to smooth things over with parents due to her bullying another child or fighting with them. P3 went on to say:

Sometimes parents would call and would be upset about something, but we always seemed to work it out with the parents. We would meet with the parents. We've even gained friendships through that, believe it or not, through a parent that called. She had said she was going to kill their daughter and they were just not getting along in school. We started communicating with this family and we became friends with this family.

Children with FASD do not often pick up on the social cues that are associated with bullying, whether they are the bully themselves or the victim. This was seen in listening the stories of the participants. The bullying that their child faced had an impact on them but many times, they did not understand that the bullying was taking place. P2

stated that her daughter often would talk about how mean the kids were to her at school. She thought that was the way that everyone acted towards each other and would often retaliate herself and have many outbursts due to this.

Theme 2: Consequences of Inappropriate Actions and Behaviors

When asked the question, “Tell me about any experiences of your child being treated differently because of his/her diagnosis you may have encountered”, following up with “Can you tell me if there was ever a time your child experienced being singled out in the classroom?”, all six participants were ready with a story or two of things that happened to their child. Within this theme, the subthemes of mixed sentiments and reactions and exclusions are embedded into it.

Being singled out for her behavior was something that P6 found happened a lot to her daughter. She mentioned an incident that happened on a school trip.

Something, and so this happened so many times that one time, she went away on a school trip and there was a girl there, and her and the girl ended up having a bit of a sexual encounter on the school trip, while a counselor and a teacher were in the building, but it was at night. She, I don't know what happened. She kind of, I guess the girl told people. Then they started bullying her about it, so she said, "You know what? I've been assaulted." She went to the teacher and said, "I was assaulted by this girl." At that time, that's all they knew, she was saying that she was assaulted with a hairbrush by this girl. First night of the trip. It was a three-day trip. They didn't call us and tell us until they got back. Well, she told me when she got off the bus. Oh yeah, and so we went to the school and they were like,

"Oh, we were going to call you about that. They isolated her from the rest of the group. Nothing was done to the other girl. Nothing. We had, oh my God, we almost – We called the superintendent. Yeah, of the schools. It was bad. We called the police. We brought her in. We flipped out on them completely, because we're like ... Yes, I get it that she cries wolf sometimes, but first of all, this is an assault we're talking about, so you should have called us right away. You should have called the police. You should ... No matter what, you have to take this serious, because what message are you giving her right now? A kid that already feels like nobody cares, and she just told you she was sexually assaulted, and you isolated her and then showed her that you don't care.

P6 also talked about other things that happened at her daughter's schools that were inappropriate and were a result of how her daughter reacted to things.

She gets used a lot, and she can't understand why he'll just ... She's like, "He'll just have sex with me." She's like, "That's okay, that's all I want, too." Then she's also crying because she's like, "Why doesn't he like me?" It's like, "Well, you had sex with him within five minutes of meeting him." She once took the school computer and you know, there's a school chat that they can go on? She offered teachers and staff blow-jobs in the- Students. Yeah, staff and students blow-jobs in the hallway at 3:00 for anyone who wants it. She put it out there. Thank goodness a staff member saw it. They called us and went to the school. She said, "she just wants them to like her." Yeah, and she's been sent home... At one school where she was, she once locked herself in a bathroom with a boy to have sex, so they were

banging on the door outside trying to get her out. They had her with a one-to-one for a long time. Another problem, we had in school is that, so she cried wolf a lot, right? It's not really crying wolf but to her it's very, "They've hurt me. "So in her mind, it is something, a great injustice was done to her, but the school... In reality, it wasn't a great injustice, right?

P5 thought of different things that happened to her son while he was in school.

One incident that she clearly remembers is when he was only 5 years old.

I remember his principal in his one school, we got a report back and it talked about what benefits, or how they can help him and help him keep calm, because he would get so aggressive that, again, they would have to clear out the classroom and they would try and calm him down. We gave them earlier reports, we had conversations with them, and we said, "This is what he needs." Then, one day I got a call at the school, and the secretary was like, "You've got to come and get your son, he's destroying the principal's office." I'm like, "What?" He was five. I went in there. The principal, he was acting up in class, so the principal locked him in his office and stared at him through the window of the door, yelling at him, and he's surprised that my son grabbed a hockey stick and started smashing things. A kid with an attachment disorder, that has potential ... At this point he wasn't diagnosed, but potential FASD and high anxiety. What are you doing? He's known for violence. That's how ... This child was beaten when he was not acting properly, at a very young age. Violence is all he knows. Exactly. It's survival, and I'm like ... You know what pissed me off? Is that the reason why he acted up in

class is because he took in a stick off the bus. Took in just a normal branch, tree branch, stick. It wasn't very long. He was five. It was the size from his finger to his elbow. That's it. They said, "No sticks," and instead of saying, "Why don't you put it over here and you can take it after class," or anything like that, they just ripped it out of his hands, and they're like, "No sticks," blah, blah, blah. He freaked out, and that's when this whole thing started. They ended up in kindergarten suspending him because of that for three days. The first day back, we go to pick him up and they said, "Oh, come in the classroom, come check this out." We go in the class and they're like, "Look, he found this stick outside and he's drumming. Isn't this great? He's got a stick that he's found outside and he's drumming." I'm like, "You're sending him such mixed messages." Yeah, okay, so he just got back from a three-day suspension and the very next day, you're praising him for bringing a stick in.

They did not know how to deal with him and sent him mixed messages to his actions. To them his actions and behaviors were unacceptable, and they were not looking at why he was acting that way. Another incident where he was treated badly had to do with his "lisp. "

We got called two weeks later for something, again. Oh, he got suspended again in kindergarten because he kept calling a kid gay. I looked at him and I'm like ... He's like, "We have a zero tolerance for that." I said, "I really doubt that my son... He's got two moms. Two lesbian moms. I really doubt my son at age five is using that as a hurtful thing, because it's always a very positive thing in our home." I

asked him, “Did you have a conversation with him?” They’re like, “Oh, we don’t want to have a conversation with him, because he just gets very aggressive.” I said, “Well, did you have a conversation with this kid’s parents?” They’re like, “Well, we had a conversation with Gabe’s parents.” I’m like, “The kid’s name is Gabe?” He’s like, “Yeah.” I’m like, “My son has a lisp.” “He’s not saying gay, he can’t say his name.” That’s when they were like ... I took my son and I’m like, “You know what? You don’t have to worry about the suspension. He’s not coming back to this school.” He’s like, “Well, don’t do that now,” and I said, “No, we’re done.” Then I put him in the car and moved him to a different school.

P3 also talked about different incidents that happened at school and at home. She mentioned that her daughter had a lot of difficulties.

It was just incredibly a lot of difficulties with her. Like expelled from school, expelled from their athletic, expelled from sports teams, expelled from a lot of church clubs, expelled from babysitting a nursery in a church. The store owners would come to our door or call and say she’s not welcome in the stores because of theft. So it was to a point where she wasn’t allowed to be anywhere and she was dangerous at home, doing very, very absurd things at home. She’s been singled out for things. But I don’t know if in front of her peers, unless there was some fight that would break out in front of the class. Like the one I mentioned before where a parent called, that happened in a class situation where she was saying... I don’t know what the disagreement was about, but something, and then she really called this other girl out and said really bad things about her killing her and all

that kind of stuff. Well, she denied it, but the teacher and the classmates all heard it, right? She does so much lying. But she stole her coaches' iPhone out of the change room, and the coaches' bag. The coach had left it on the table or on the bench, whatever, in the change room. She would go in there during practice time, and she stole her phone. It was a very trusting school where people would leave their things out, but they had to kind of, the principal said, you can't assume, you just have to clean up all your stuff and not leave valuables. I mean, the coach did get it back. It was the assistant coach. She got it back, but at the expense of having lost a lot of her, I don't know, pictures or something, because she had tried so hard to tap into the phone to get the phone and hadn't been able to, so she lost them all. She didn't see anything wrong with what she did. So it's almost as if she isn't aware that is she sees something, she just assumes it's hers.

P1 commented that her daughter felt excluded and singled out for her behavior. She mentioned the following:

She often commented that she was not asked to join to play with others, not be invited to birthday parties. (she had a party and sent out invites- not one child came to the party from her class- very disappointed). She was removed from the school bus, removal from the class, not permitted to attend some group activities due to behavior choices, removal from class activities due to her inability to be able to control her outburst.

Being treated differently was common for the daughter of P2, she told me that her daughter would have full blown rages.

Other parents became aware, some understood, some did not. She was ostracized and excluded from a lot of extra activities outside of school. In public areas she would have a tantrum she was looked at differently. No one can physically see her disability, many misunderstood her. She never mentioned being singled out, but she would talk about how she felt after a meltdown and felt everyone would be looking at her.

The actions and behaviors of the participant's children were inappropriate but were also met with mixed reactions and sentiments from the school, the children around them, and their parents.

Theme 3: Contradiction of Parents

One common theme that was very prevalent from listening to some parents is that they often contradicted themselves when talking about the support given to them from the school and the community. P3 told different accounts on how her daughter was supported. She would say the school was amazing and supported her well but then she would say if there was trouble that she would just go and get her, and nothing was done to her. Even though the school was amazing according to her, the school did nothing to help her daughter and eventually her daughter had nowhere to go.

She had trouble in school, like principal involvement, like every year. And I said, I know this is frustrating, always getting these calls but I want to nip it in the bud. Let's deal with it. Maybe we can deal with it. She wasn't on an IPP or anything like that, or I shouldn't say never but she had problems. The other children were amazing, amazing. Even though we had problems with the

children and the parents, we could talk to them. I have told the teachers and the principals, how blessed we were to have kids in school that tried to overlook. So that has just been excellent, really, really trying to, cause there's not very many kids like that in our school. So they really tried to, to still be kind to her and to, to realize that she's got a lot of baggage. If she did anything, we smoothed it over with the parents. The teachers and school personnel? Just so excellent. I just can't give them good enough marks for how good they were with her. Like I said, we had very few FASD kids or even Aboriginal kids in our schools, very few of them. Our principal came from an Aboriginal community and she was so good. And the teachers were so good at just amazing, just really amazing. We were in real good communication, always with the schools. Teachers would always email me about issues and things that happened, so very good. If things happened, they would call me, and I would come and get her and take her home.

When asked the questions "Was she treated any differently because of her FASD for any things that she did in school?", P3 wanted to say no, but

she said she didn't want to just sound like there was nothing that I just can't see it, it was just a very good school and very good class. Very good peers. Very good principal and teachers. She's been singled out for things and she does so much lying. When she stole the coach's phone, we met in the principal's office with the coach and her and the principal and me and, and this, he didn't own up to it that she had done it. But the principal saw this phone in her back pocket during school,

when the coach had already reported that she was missing it. So she just did not, I want to use the word ever, but I won't be quite as far, hardly ever own up to something that she was, there was proven she had taken or done, but she would not own up to it. He didn't assume it was hers, but I think she assumed she could take it and just lie about it. We just gave the phone back and that was that.

I just took her home. So the community was really very supportive, you know, and bending over backwards, you know, helping out with her. So once at one store and other stores, they just said that staff had seen her take something, she's been caught even on the camera, on the video camera as well. And I saw her home with stuff from that store. But once again, she's like, no, she didn't steal it. She bought it. And even it was the drugstore that called and said she was on video. They caught her on the video surveillance, and they said, you know what? We'll let it slip. This is the first time we've caught her. But, let her be warned that this is a warning for her. The community was very lenient with her, but she wasn't allowed to go anywhere. They were very supportive, but they wouldn't allow her in the stores, she's not welcome in the stores cause there's theft.

P1 also had statements that were contradictory to what she had said. She mentioned that there was lots of support but then she would say that there was none, lots of changes made.

There were a lot of empty promises. We could discuss, brainstorm, and come up with promising support during the team meetings, but they would not come to reality. There seemed to be excuses of miscommunication and reasons for the

follow through to occur. She was in the same classroom with the same teacher and students for 2 years. There was support plan in place for monitoring her behaviors, and she had an educational aid assigned to her to help support her in class and with her programming. She had weekly or bi-weekly time with a school psychologist who came from an outside source. The teacher communicated to the home daily through a communication book and regularly emailed or texted and called to keep everyone informed about how things progressed during the day. I felt supported and they genuinely cared for her. They made every attempt to include her in the classroom and support her wherever she needed support. The school was very good at communicating with the class and ensuring that everyone was fair and caring. It was a constant building upon and starting a new fresh day after a day of poor choices. Each day was a different day, some positive while others were very draining.

When asked the question, “Do you feel that the school personnel treated you differently because of your child’s diagnosis?” and “What challenges did you meet from the school personnel?”, P1 described the treatment of her daughter in the following way:

Yes, with the amount of support they provided and how they approached the situation. They were very genuine, sincere, and concerned. They wanted to help make her school days successful and bring some normalcy to her world. They were always prepared with many backup plans on how to approach the day. She was not able to ride the school bus due to behavior, I had to bring her to school. Other challenges I met were that I had to pick her up at school due to behavior,

changes in plans, trying to find something that would work for her. They would have the entire class removed from the classroom if she misbehaved. Plans were always changing, and I sometimes didn't know what would happen next. After many, many months of waiting, she was receiving counseling, very little trauma support. The counselling should have provided far more trauma therapy. Even though the school was supportive, I would have to go to the school in the middle of the day and take her home if she was not acting properly.

Listening to the stories of both P1 and P3, it was noted that even though the school was amazing and genuinely cared for their child, it seemed that the support was not there when it was needed. Instead of supporting and providing services for their daughters, they were called to the school to come pick them up and take them home.

Theme 4: Bias and Racism

Bias and racism was noted throughout the stories that the participants shared while answering the interview questions. Subthemes that were noted under this theme were prejudice, guilt, shame and stigma. As well, in order to get an assessment, the wait time and the procedure to get a diagnosis was a difficult procedure.

P1 stated that her daughter was already diagnosed when she got her. Her response to the diagnosis was alarming.

It was overwhelming when I read the many, many, many pages of her report and all the various concern elements. For a young 8 years old, she had a very comprehensive report and diagnosis. Very alarming and concerning. My heart was torn, and I needed and wanted to learn as much as I could to support her.

P2 knew immediately when the child came into her home that she had a disability of some kind. She said that the transition to their home was hard.

It took a while for the FASD assessment from the referral to the time it was completed. Despite the support the child received from their school was fabulous. There was a lot of paperwork to fill out as expected. Unfortunately, due to her age the results were FASD suspected but not able to get full diagnosis.

Recommendation for another assessment when she was older. The suspect FASD diagnosis took 2 years from referral request. I felt somewhat frustrated because of nothing concrete just suspected even though medical records stat biological mother consumed alcohol and drugs during pregnancy. Once a diagnosis was received later, I felt bias when I got the diagnosis. I felt discouraged, another Indigenous foster care child with an arm's length of issues and concerns and nothing to support in many cases.

In many cases, the parents had to pay privately to get an assessment done as was the case of P4, P5, and P6. P4 stated that they adopted their son knowing that he did have some kind of disability.

We knew there's a possibility of drug and alcohol use just based on all the information they have on his birth. Mom said she was an alcoholic, but said she didn't drink during pregnancy, but she also didn't get prenatal care. We paid for the diagnosis privately because there was nowhere in our area at that point in time to have been diagnosed. So yeah, it ended up going on a credit card and it was paid, and we went, got a neuro educational neuroscience at a psychologist. We

tried to go to a pediatrician at first but like, not like there wasn't anything available, so they all could say, Oh, well we think that he has, but we don't know. We can't say for certain. And he needed to go developmental pediatrician went through them first. We went to regular pediatrician. Then we went to developmental pediatrician. Nobody could help us. And they basically said, you need a neuro psych in order to tell us this is what you need to do. And there's nothing available here. We knew he was probably, probably had FASD when he was three. When he finally got this diagnosis, maybe 10, 10. Wow. That's yeah. And it took about two years to get the paperwork, and everything done because she's very slow. She has so many clients and she takes forever to get everything done. And then everything had to be in stages. She wanted to have a sleep study. First that took forever. Then we had to, you know, like every there's no sleep study spot except in Toronto. And we had to go for that, and they want all that kind of stuff first before then they'll do the medical piece that like doctor, doctor piece. Doctor says yes, but you still need the neuro psych piece to back it up. So anyways it was a very long process. It was about two years with her alone.

When asked the questions "Did you experience any bias or any prejudice when trying to get your diagnosis?" She told me what some people commented to her.

At first people would said, why do you want to do that? Why do you want to label him? He's gonna be stuck with that label for life. He'll grow out of it. He just has to mature, you know, stuff like that. And it's just like, I mean, and that's not just from some might be from medical professionals where they said, are you sure you

want a diagnosis? Like you want that on his record? I'm like, well, yeah, yeah. I wanted it down on his record, my mom, people to know that he has disability and it's not a behavior. Like it's a symptom of his disability because you can't tell by looking at him because when he was younger, like he could tell that it, he was, he was different. Okay. We knew he was different. Like you could tell by his eyes at first it looked like kind of like down syndrome. I was like, no, we think, but we had already helped raise a nephew with FASD. So for us it was like, we went into that option knowing that he probably ended up FASD and we knew for sure that prescription drugs have been used. So we, we had, they had that actual in paperwork. So our son was officially, I think it was officially ARND when they first diagnosed him. But because it was a two-year long process that changed in that time. So his diagnosis from the doctor says ARND but his diagnosis from the psychologist says FASD without features. So we knew all of that already. But people don't want to know. No, they, it's very stigmatizing because everybody knows. Everybody knows it's not like autism where everybody's like, Oh, nobody did anything wrong. It's not anybody's fault. Well, FASD they're like a, they know the child was adopted or be like, or were in care of be like the parent, the parent drank. Yeah. So, so there's a small rez like this, like everybody knows who drank when they're pregnant. Yes. Everybody knows who's been out partying, but for them to actually sit through a support group is almost more stigmatizing than having gone out and drank in the first place because it's like, okay, now we're admitting it to everyone. Like publicly, like oops. And most of them are

like mistakes that didn't... By admitting it, it's putting more of a stigma on them themselves. I think society is like that. Yes, absolutely, I think that, that makes that person super brave. They stepped up and asked for help, but yeah, that's not how society sees it. Not only that but his school treated him bad. It's hard because there's certain people there's racism against white people and I mean that or non-Indigenous people, I'm white, that's part of the disagreement here, and that happens within any culture, race. What's difficult when our son has to deal with that. And he's not even white at all. He's just Indigenous. Both of his birth parents are Indigenous. His adoptive father is Indigenous, but my husband didn't go to long house and because of that, they treated him badly. So it's frustrating to me that he had to deal with that. But like it has no bearing even on his skin color. And that it was frustrating that all they can see is the negative.

P3 found that there was a little bit of prejudice but not much. Finding a diagnosis for her took a little time.

I felt that there was sometimes a teeny bit of prejudice because she was a different skin color because she was Aboriginal, but very little. It was more because she was Indigenous and not FASD. Social services and the FASD coordinator said she met the criteria for FASD. They would always just from me talking to them or, or the different things, not like we went through a checklist and like okay, yep, yep, yep, yep, yep. Like that officially on paper, just like so many of the things that we were dealing with was just bang on with FASD and her mother did drink, does drink, like, it is very known that she's had a lot of children 10 children. And

I don't know if any of them are with her currently. Right now, she is in the courts with drug charges and stuff like, so that is definitely, that was definitely her lifestyle, a lot, all her life.

P5's son struggled with difficulties at the school. She continued by saying:

My son had a lot of struggles in school, kicked out of school He's been in a lot, a whole bunch of different schools, so did it change the programming? No.

However, we fought his entire childhood getting services he needed with school, and then all of a sudden that diagnosis is gone, and guess what? He's in a regular classroom with regular kids, and no more fights. We tried every recommendation that all the different organizations and people involved wanted. I'm like, Do you know what? We've tried all your recommendations. We've tried the psychiatrist's recommendations. Why don't we try what he wants? He wants a regular school and a regular classroom. He says he can do it. Why don't we give him that option to try? They would never listen to me, and then the FASD diagnosis went away, and all of a sudden, they listened. Because he was no longer labeled FASD, then all of a sudden, they can work with him and put him in a regular classroom. They constantly said, "Well, we don't have the support for him. "Nobody ever said specifically that the FASD diagnosis being gone was what changed things, but it's just too coincidental. He was really violent, extremely violent. I've had five concussions, three broken bones. We've had \$10,000 damage to our car that he did with his hands at the age of 10 -11. We said something had to be done. We ended up putting him in a treatment center and before he could come home, we

did a VTRA at school so everyone was on the same page. I basically told them, “I’m showing up with him on the first day of school, at your doorstep, so be ready.”

At his first school, I said to the principal after his first suspension, I’m like, “Did you not read the reports?” He was like, “Well, no.” He was like, “If you get all the professionals and get them together and have them come in, and you call them and tell me when, we can talk and then I can find out the stuff.” I’m like, “They’re only going to tell you what’s written right on those papers. Read them.” If you have to, get someone else to read them and give you the Coles notes. He didn’t want to bother. Getting back to his diagnosis, he was eight, decided to get him tested and what happened is, his marks came back as not having FASD, but it was a week and a half before his birthday and they said, “if we took all of his results and put it to a nine-year-old” which is what he would have been in 10 days, “then he would be FASD. “So they said they were putting him as high risk, because if we would have tested him three weeks later... that’s what they told us. anyways. The school couldn’t support him because of him being at high risk. He got tested later at our expense and he’s still labeled a high risk but it’s really kind of messed up because he had a lot of trauma in his early childhood, so what’s the trauma, what’s the FASD? Having an alcohol-based brain injury, but whether it’s FASD or not is the question, right? He scored not FASD on his last test, but it was after he spent a year and a half in a treatment center. He had all his behaviors down pat, so it’s still up in the air, but technically right now, he is not diagnosed with FASD.

P6 said the school did not understand FASD. The school was more focused on the MID (Mild Intellectual Disability) diagnosis for her daughter than they were on the FASD. She went on to say:

Because of this, it came back to bite them once she got in grade eight, because the FASD comes with a whole.... She's a high sexually active child. Hyper-sexual, her impulse control is almost non-existent. So many things, so they, all of a sudden in grade eight, had to focus on FASD and had to learn more. Even though we always provided them with the information, we always said it first, we always told it, they only focused on the academic. They wanted to switch her to a class, not an ISP class but, it is an ASP class. An alternate support place. Yeah, all because of the MID diagnosis, be we said, "You know what? She just switched schools. That was very traumatic." She had switched schools within the past month. They went and segregated her from the students. She doesn't understand. She has trouble understanding her disability. The most she'll say to me sometimes is, like the other day she said to me, "I hate that my brain is like this and that my birth mom did this to me." I tried to explain to her that her brain is just different. It was hard to get supports for her. There was two years where she was really bad, lots of symptoms, and it was really tough. We didn't really have the support. Because of her actions, she is known through the school board. They've obviously had discussions about her, because we'll go to meetings for our son and they'll say, "Well we wouldn't recommend this for your daughter, of course, but we'd recommend it for your son." We're just like, "Oh, you know about our daughter?"

Okay. We didn't have a conversation about our daughter, but you know her from reputation and reports about our daughter." There's bias right there, towards our daughter, from different members of the school staff and from the school board. They didn't really understand FASD, that you're treating the behaviors as behaviors and not as symptoms of FASD. It's really frustrating, but they're starting to slowly move around with her. It's like, it's not that she should be exempt from doing this. You just have to tell her in a different way of what you need to get done. The thing we got a lot when it comes to workers with her, or teachers in schools, is that, "Well we don't have the time to put in the effort." They don't put it that way, but they, basically, "We don't have the time to do the extra steps." It's like, "you don't have time to go chasing her around the yard because she ran off, and you don't have to time to deal with clearing out the classroom because she freaked out." You know what I mean? They look at it like you're enabling the behavior and you're just being okay with the behavior but it's like, she doesn't get angry because she's a bad kid. She gets angry because she's overwhelmed and her brain is on high. They had teaching staff there who said they'd never been exposed to this before, they had no idea. We found out about FASD when she was about 8 and had her tested. She had an ed psych done at school but we went to the FASD clinic to do the FASD thing. It was like a three-day Assessment. When she had her ed psych done at school when she was just starting grade two, because we just started to notice learning issues in grade one. At that time, she tested mild intellectual disorder, MID. Then she had another one

done, oh, probably about grade five, six. We initiated that one, the FASD one. We initiated that with the hospital. We went to the FASD clinic, and at that point, they tested her for a variety of things. They tested her fine motor skills. They tested...they did the psycho ed again. They did facial structure, and speech language. Now she's going through another assessment right now at the treatment clinic.

Theme 5: Supports, Resources, and Recommendations From Parents

Many of the participants noted that the supports and resources in place for their child did not always meet their needs. They stated that a lot of the work had to be done on their own with them advocating for their child to get things done. In addition, when asked the question, "What kinds of supports are in place for you and your child?" as well as "What suggestions/advice do you have for other parents or guardians of children with FASD?", a number of them came up with the same suggestions.

P1 to P6 stated that they did a lot of self-education and webinars. They also looked for any workshops/courses to further educate themselves. P1 also mentioned that:

Our family doctor was helpful as well with education on various elements of her behaviors and daily episodes. Counsellors, play therapy, medication, school counselors and social workers were put in place to support her. I also got foster care respite relief and counselling support, as well as social worker visits periodically.

P2 continued along the same way and stated that:

Educational support and support for us as caregivers either through respite or further training was provided. I reached out to other caregivers who had extensive knowledge and skills parenting children with a disability. Our daughter was involved in therapy addressing past traumas but this has not been in place for over a year.

In addition to this, P3 mentioned that besides the support from other caregivers, she got information from social workers or FASD coordinators. P4 worked in special education classes and was involved with students with FASD. As well her husband's nephew had FASD so she was able to find lots of resources to help her.

We had lots of experience with our nephew, so it was just like him again. Okay. So it was part two. He's very similar. Well, in my husband's family, so it's, it's his sister's boy and she didn't know she was pregnant again. And like, she didn't, I think like, it doesn't take more than once really. Like, people don't know, but like when people are bingeing or whatever, they don't know they're pregnant, that's what happens. Anyways we had lots of information from there. I started attending workshops and stuff on my own. Finding information online and going through all the references at the end of like notes and stuff we got. So I'd go back and I'd read their original article and stuff that they wrote so that I could get even more of the medical kind of part of it too, so I can understand. There isn't a support group on this first nation but there's one on Six Nations next door. So it's like not far away. And then there's one off reserve, but there isn't one on this first nation itself because this one is so small.

P5 and P6 had similar experiences when it came to find resources for their child. They both did their own research and attended workshops and conferences to find out as much information as possible. They advocated not only support for their child at school but also for support for themselves. P5 mentioned that she has only recently been able to get support.

I fought for so long to get supports for them that helped us too. I got a respite worker, but she was older and she's like, "Now that she is grown up and she got more needs, we just can't do it." She would take her out for an hour but said that she no longer could do it. I was going through cancer treatments and my partner hit a wall, had a nervous breakdown. They ended up helping us find a treatment center and helping us get her in. We had to do something as she was running away, inviting strange men to the house for sex, she tried to steal the car, and took money from us. We tried to find the right supports, but it was hard. We were able to set up some supports, and then also build our support network around us as well.

P6 also commented on how hard it was to get supports when it was needed. She did a lot of self-education for resources and finding out what was out there for supports but to actually get them was a difficult process.

So I called CAS to help us. I just said to them, "You know what? You guys are not helping. You've had the reports of the violence in the home from everywhere. You're not helping. You're facing an adoption breakdown if nobody helps soon." I said, "Now I'm on my way to Toronto, for my spouse who's going into surgery,

and when I get back, I want solutions on the table and some supports.” They passed the file to KGCFCS which is our First Nations Children’s Aid type of organization, who then called us, and they had no solutions. They said, “We don’t know what to do with your kids.” They said, “We can’t even place them in a foster home because they’re not safe. They’re deemed too unsafe to be in a foster home.” They said, “We can’t take them off your hands even to give you a night’s respite.” They ended up finding a treatment center that would take them, but they came home early and we had to send them back. Finding supports to help us and them was difficult.

When looking at what the different recommendations that they suggest are needed for parents, they all said to get educated on what FASD is. P6 added to this by saying:

I think the main thing would be to make sure you stress really hard the FASD and get them every bit of information you can, because a lot of time, it’s like, we would take the recommendations and we would be overstepped when we started talking about FASD and it’s really important that they understand the difference between FASD and then other things they might see in the school. It wasn’t that... Once we learned, too, to put in our me time... You still have to have them in mind. We’d have to schedule it in, or, so they knew and you knew that this was the time, but then you had to keep up with that boundary. It’s really important. It’s so incredibly important to do that.

P6 said she would give this advice to other parents:

My advice to other parents would be to fill their cup, and not take things personally, and focus on one day at a time and keeping their kids safe. That was the best advice I ever got, was that my job right now isn't to make her happy. It's to just keep her safe while we get her through these hormonal years. Once I started thinking of it as, "I'm doing this to keep her safe," and I might not like it. She's five hours away right now, six hours away. I don't like it. It's not ideal, but she's safe. For years, we didn't do the self-care. We just kind of went and went and went, and I had people tell me. My boss even told me, she said, "You're burning the candle at both ends. You're going to burn out. I'm watching you; you're going to burn out." I would say, "No, no, no, no, I'm fine. I'm totally fine. I can do this." Then one day I crashed, and I was having...Almost, I was having heart attack symptoms, and then my short-term memory went completely, and my spouse would find me at different spots in the city and I didn't know why or how I got there. My brain just went. So remember to do the self-care.

P3 had strong feelings on what other parents should do. She strongly stated that:

...being consistent and having a routine, going to bed on the same time every day and all these things would be very helpful. I guess it's hard to say maybe it was helpful. Maybe it would have been worse if there hadn't been as structure, but it's still, still didn't work. Yeah. I felt consistency and keeping things simple with instructions and not overwhelming them with too much would help. And of course, loving them all the time helps, which is a challenge, I must admit. There was times that it was like, help me God to love this child. I need to love her. She

needs to be loved. And we had a great community. We had, we have excellent church family. We had actual excellent other families that would help out and bring us meals sometimes when it was really hard. You need the support from your community and church.

P4 continued with statements recommending documenting everything that has happened.

Write down everything. Every time you talk to the school, every time you call the school, every time you email the school. Have a paper trail of everything so that you have stuff to back up what you have to say. Like I talked to you about this issue on this date and I talked to you at this date. Then I talked to you at this date. Okay. Now we, we have proof and we can go to the next level. So don't be afraid to go to the next level. So if you've talked to the teacher, talk to the principal, talk to learning resource teacher, you get tired of communicating with them. They'll get tired of talking to you, but it's your child. So go advocate for them. And I think, I think honestly with FASD, like the families need to be the ones that are guiding the teachers on what their child needs. So the child, like it's not always going to be the teacher saying, Oh, you need to learn this. No, the parents need to really push. This is what we need our child to learn next. This is what will make our life easier. Or our child's life easier or them more confident or whatever it is. Like we sat there and asked our son, what do you want to do? What do you want to learn? How to do, what do you like to do? So he's working on cooking lessons right now. They need those life skills. I would start with what the family wants because, and things that they need, they know their child the best, especially these

guys are hard to learn hard to get to know sometimes. Casus a lot of them has so much. Yes. Especially if they've been through a lot of different care homes and stuff. Also, I think every foster and adoptive parent needs to be explicitly told and they need to like sign a form saying that this child could have FASD. A lot of people don't know that. It is important to have background history to help the child.

P1 and P2 both stated that you need to work together as a team, work with all the team players – outside of school agencies of support and in-school support. P2 commented that it takes a community to raise a child. As well, as agreeing with what P2 stated, P1 also mentioned:

You need to become educated, find support, push for consistent support, inform authorities who need to be aware of the lack of follow-through with the support promises made, keep in communication with the school, don't be hard on yourself, take it one day at a time, have a plan, let your child know the boundaries and expectations, take breaks when needed – respite, don't do it alone.

Summary

In this chapter I presented the results of my research, including the five themes that emerged from the interview questions. Along with the results of the study, Chapter 4 also provided information on the pilot study, participant demographics, data collection procedures, data analysis, and evidence of trustworthiness. During the coding process, five themes emerged to support the research question. All five themes were supported with the responses given by the six participants.

Chapter 5 further interprets the study findings to provide a deeper insight into the results. Limitations, implications for social change, and recommendations will also be further discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

Summary

The purpose of this study was to explore the perceptions that parents of Indigenous school-aged children with FASD have of their experience with school personnel and to examine if those perceptions of their experience included stigmatization. The research question “How did parents of Indigenous school-aged children with FASD describe their experiences with school personnel?” was used for the study. The nature of the study was qualitative, using a narrative approach for the research method. The narrative approach allowed the participants to provide rich detailed information relevant to the support they received for themselves and their child.

The participants were six parents, foster or adoptive, that resided in various parts of Canada. Interviews were conducted via email, Zoom, or telephone with an audio recording of their conversations where applicable. The interviews lasted approximately 60 to 90 minutes in length using semi-structured, open-ended questions that allowed for follow-up questions if necessary. While listening to their stories, I was able to learn more about the experiences each participant went through with their child and the frustration that they felt with the lack of support and resources available for their child.

Throughout the data analysis process, I identified five common themes that were associated with the participants’ experiences. Each of the themes also had sub-themes emerging from them. The five themes were as follows: impact of bullying; consequences of inappropriate actions and behaviors; contradiction of parents; racism and bias; and supports, resources, and recommendations from parents.

The sub-themes that emerged from the impact of bullying were shunning, apathetic and negative feelings, indifference, avoidance, dismissal, detachedness, and lack of interest or concern. These sub-themes focused on the different aspects of how bullying impacted the children and parents in and out of the school setting. The spillover that occurred from bullying was seen in a variety of ways. The second theme, consequences of inappropriate actions and behaviors, was sub-divided into mixed sentiments and reactions, as well as exclusion.

Within the third theme, contradiction of parents, inconsistency, and denial emerged from the comments made by P1 and P3. Bias and racism was the fourth theme that emerged from the findings. Sub-themes noted under this theme were prejudice, guilt, shame, and stigma. The last theme, supports, resources, and recommendations from parents focused on what was made available to them, in addition to what they themselves had to do to become better educated and advocate for their child. In this chapter, I will discuss the interpretations of the findings, limitations of the study, implications for social change, and recommendations for future research.

Interpretations of the Findings

The theoretical framework for this narrative study centered around Goffman's social stigma theory. According to Goffman (1963), the term "stigma" describes the "situation of the individual who is disqualified from full social acceptance." This was shown in the findings of the narratives that were given by the participants in this study. These participants relayed how their child was not socially accepted by their peers and others. As P5 stated,

they have to look at the child first, not the behaviors or actions that are related to FASD, but that is not what is happening. They are looking at this child who has difficulties controlling their anger, their impulsions, and outbursts. They are not accepting her or supporting her as an individual at school. She is excluded from many things and often they don't believe what she tells them.

P2 also stated, "I felt discouraged, another Indigenous foster care child with an arm's length of issues and concerns and nothing to support her in many cases." She mentioned that her daughter was also excluded from many things.

There are gaps in the research in relation to how public attitudes affect Indigenous people with FASD. Goffman (1963) stated that stereotyping, labeling, and discrimination have affect the attitudes associated with stigma. This was shown in the participants' responses. P4 stated that many asked her why she is labeling her child. She stated, "They thought by having him diagnosed that she was putting a label on him that would add to any negative perceptions that people already had about him."

As FASD is often considered to be a "hidden disability," as shown in the research done by Miller et al. (2017), it is not often identified as FASD. P3 mentioned that her daughter did not have the facial features and one could not tell she had FASD, but her actions and her behaviors leaned more towards FASD than anything else. P6 also said that her daughter did not understand it all. She looked fine and thought she was fine. As such, P6 relayed that the school did not understand FASD or even recognize the effects that FASD has on a child. Alton and Evenson (2006) stated in their research that it is important to recognize the primary disabilities and the secondary disabilities that develop

from FASD. This was not the case with the daughter of P6. They ignored her primary disabilities until the secondary disabilities kicked in. P6 said, “They were more focused on her MID (Mild Intellectual Disability) and not her FASD, until she hit grade eight and a whole new set of problems associated with FASD set in.” It is essential that all aspects of FASD are recognized and supported so that early interventions can be put in place.

Recognizing the different experiences felt by Indigenous families, shame, mistrust, guilt, and the immense impact on how these feelings are affecting them can be felt in generations onwards (Barnes & Josefowitz, 2019). As my former colleague had stated to me, “Bringing up the guilt and shame they feel is not a good thing.” In addition, P4 stated that “everybody knows who is out drinking, but to admit to it publicly, it is more stigmatizing for them.” FASD does bring forward stigma, guilt, and shame. This stigma is widespread and felt by them. These thoughts and insights to their experiences were noted as emerging patterns in previous literature, as well as their personal narratives.

Research has shown that admitting to drinking while pregnant, disclosing information to get their child diagnosed, or seeking help is not always done (Niccols et al., 2014). P3 and P4 both said that getting the history of the birth mother is very hard. P4 felt that this information should be part of the adoption process and that it is very important to have the background history of the child’s birth. Having this knowledge would make it much easier to have the child diagnosed but getting this information and having a birth mother admit to drinking would require more advocacy on supporting the child and less prejudice and shame put on the birth mother.

The majority of the participants noted that the support given to their child at school was all over the place. P5 and P6 said that the school did not know how to deal with their child due to their diagnosis of FASD. The literature has shown that most educators do not know how to provide the necessary support in the classroom to help children with FASD (Canadian Teachers Federation, 2015). The trauma and violence that many of these children face in their young life is the result of what happened to their parents. The literature review also revealed that intergenerational trauma is seen in many Indigenous families and the trauma from residential and/or day schools has severely impacted their lives. P4 stated that her husband and sister-in-law attended day school, and the impact on their family is still being felt. She mentioned that her sister-in-law would go on binges but would not admit that she drank during her pregnancy. Her sister-in-law had a child who is FASD. This information provided by P4 aligns with the research done by Samaroden (2018) and Popova et al. (2017). These experiences felt by her husband and sister-in-law not only affected them but also affected all members of their family through the generations.

It has been shown that the stigma, guilt, and blame resounded with the children of all the participants as the teachers and students focused more on the negative aspects of FASD instead of the positive attributes of the child (Morrison et al., 2019). P1 and P2 stated,

There were times when situations occurred due to their choices and poor behavior that caused other students to laugh at them or mimic them and we had to remind our child that things sometimes happen and that is was difficult for them to

understand the disability. The other children didn't see the good in our child but saw only the outbursts and other behavioral displays.

Child stigma can be also seen noted in the stories from the participants. Child stigma is based on the observation that children frequently label those who are perceived different in various ways resulting in oppressive actions (Goffman,1963). Name calling, exclusion, and snubbing all relate to the stigma felt by the child.

Previous research also showed that social isolation, exclusion, and lack of understanding often lead to stigmatization, guilt, and shame (Morrison et al., 2019). These are shown in the themes that originated from the participants' responses. FASD-related stigma is prevalent in the research done. The participants noted that their child was discriminated against because of their diagnosis of FASD. Bell et al. (2016) stated that understanding the negative stereotypes and attitudes brought by both the labels given to children and their behaviors is extremely important because these have the potential to set children up for negative educational outcomes, underachievement, and delinquency, and may subject them to lifelong stigmatization beginning in childhood. Focusing on their FASD and not the child brings stigmatization to the forefront.

According to Wing Sue (2010), bullying is also often the result of not understanding something, particularly with a child who is different from the others. This form of bullying, or microaggression, can be seen in snubs, exclusions, insults, or name calling. All the participants noted that their child had been bullied in some form, as well as their child being the bully themselves. P3 said that her daughter would blame everyone, threaten to kill them, and fight with them. The daughter of P6 had trouble

understanding her disability and was often in the “flight or fight” mode. She would become violent and swear at the other students at school as she was very reactive and did not understand why people did not want to be with her.

Mental health issues often are one of the secondary disabilities that emerge from FASD (Wilson, 2013). P3 mentioned that her daughter made quite a few suicide attempts and that she had a 24-hour suicide watch on her numerous times. Finding appropriate mental health services for their child often was a difficult matter as well. P3, P5, and P6 all noted that finding a treatment center that would take their child was a difficult process. It sometimes took up to 2 years to find a place that would take their child. P5 and P6 finally threatened that there would be an “adoption breakdown” if nothing was done to support them in finding a place for their children. They all noted that this was a very stressful process for everyone.

Dej (2011) noted in his research that the experiences of parents/caregivers caring for Indigenous children with FASD was rarely researched except if the children were adopted by White parents. The reason was the stigma that many Indigenous parents faced. While recruiting participants, I did find it difficult to find an Indigenous birth parent who would participate in my study. I was able to find some Indigenous foster or adoptive parents to participate so that I was able to obtain their perceptions of the experiences they faced. The prospect of finding Indigenous birth parents to participate was reiterated by P4 and as well as a colleague of mine as being very low to almost nil as many did not want to publicly admit that they drank during pregnancy or else they did not want to bring up feelings of guilt and shame.

Limitations of the Study

The study was limited to parents of Indigenous children with FASD and excluded other ethnic groups. The study was not generalizable to people of other ethnicities. Due to the impact of COVID-19, along with the difficulty in recruiting Indigenous birth parents, the parents who participated in the study were either foster or adoptive parents. The study's criteria was maintained as the participants met the requirements set out in the guidelines. The findings of this study are representative of the narratives given by the participants. By having the participants review their interviews after they were transcribed, I was able to establish credibility with the results by verifying the accuracy of the interview. Personal narratives are at the heart of how human beings share information, represent identity, and convey ideas unique to their life circumstances (Merax et al., 2019). The participants gave their personal account, not just from a factual side, but also a narrated reconstruction of how they saw and understood the events that happened to them.

Recommendations for Future Research

The data and themes that surfaced from this study further complemented the literature written as well as added additional information about the support and education needed in the school system for Indigenous children with FASD. According to the research findings and the literature reviewed, a lack of support, and even knowledge, is seen in the school setting. As individuals are telling their stories, they are not isolated and independent but are connected to their social, cultural and institutional setting (Moen, 2006). Even though, some participants felt that the school supported them very well, it

has been shown that they did not know what to do with a child with FASD and often ignored the behaviors of the child.

The first recommendation would be to investigate the support provided to students with FASD in the school setting. It has been noted in the literature that children with FASD often find themselves without any support or interventions in place for them in the school setting. In addition, often teachers are not trained or equipped with the proper resources to support and work with students with FASD. Providing training, as well as providing resources, to teachers on supporting and educating students with FASD is an important step to take to help alleviate any stigma or pressure that the families may be feeling.

The second recommendation would be for further research to be conducted on the exploration of stigmatization relevant to the parents of Indigenous children with FASD. Literature has shown that most research is only done on non-Indigenous parents (foster or adoptive) and not birth parents of Indigenous children with FASD (Dej, 2011). As it is often difficult to do research on Indigenous birth parents, a recommendation would be to be immersed in an ethnographic study. Creswell (2014) describes this method as extended observations through participant observation, in which the researcher is immersed in the day to day lives of the people and observes and interviews the group participants. By ingratiating oneself in the Indigenous community, one becomes more vested in what is taking place in the community. This will give one a deeper understanding of the told stories, of their life experiences. In addition, it elicits a deeper

meaning from what is told and observed through the multiple methods of systemic evaluations.

The third recommendation would be to conduct more researched aimed at looking at the negative attitudes and bullying toward Indigenous children with FASD in the school. This research should be relevant to what is taking place at the school and not just an overall program on bullying. Understanding the culture, the disability, and the effects and trauma that these children have gone through would support all students in understanding what steps should be taken. As well, the research conducted should look at how the long-term negative public attitude has affected Indigenous people with FASD. Further research similar to mine would support and advocate for further studies that provide perspective and introspective observations of the lives of parents of Indigenous children with FASD in relation to educational stigmatization.

Implications of Positive Social Change

The implications of this research study comprise generating more awareness of the educational stigmatization felt by parents of Indigenous children with FASD. Parents of Indigenous children with FASD have unique insights into what is happening to their child at school and are able to convey to other parents what needs to be done to support their child to have a smooth transition within the school setting. Positive social change can occur when goals are achieved and have a positive impact on others.

This study could change how communities view Indigenous children with FASD, as well as support the parents in their day to day lives. The theoretical framework and

Goffman's social stigma theory provided a guide to explore the perceptions that parents of Indigenous children with FASD had of their experiences within the school setting.

The study could lead to more extensive research on stigmatization and include Indigenous birth parents in future research. In addition, looking at research on the development of training of teachers on the effects of FASD within the Indigenous community could be very viable and beneficial. Designing and creating resources and interventions could impact how the school supports children with FASD to create positive social change within the education system.

The literature reviewed within this study entailed themes of stigma, prejudice, trauma, and guilt. This study's findings corroborate previous studies and add to the research gathered. The findings from this study could support school personnel, as well as other parents, caregivers, and social workers, to connect and overcome the negative attitudes that surface within this topic. Parents and school personnel could advocate for educational programming that focuses on resources for children with FASD, as well as, programming that centers around eliminating negative attitudes on labelling, discriminating, and stigmatizing children with disabilities. Parents could also advocate for more support be given to them to provide self-care in order to alleviate the stress that can result from the negative experiences encountered in their daily lives.

Conclusion

This study allowed me to gain extensive insight into the lived experiences of the adoptive and foster parents of Indigenous children with FASD while documenting their stories that they related to me. This experience gave me a deeper awareness of what they

and their child went through on a daily basis at their school, as well as in their community. During the interviews, the participants expressed their frustration and at times, hopelessness they felt when their child was bullied or was the bully. They also discussed how the school did not always provide support to them and they had nowhere to turn to look for the support. As one participant said, “I had a mental breakdown at one point as I did not know where to get support and I was mentally exhausted.” A couple of participants said the schools were amazing but then also said if there were problems, they just went to the school and took their child home.

A need exists for school personnel to create programs and provide resources to help the parents and the students cope with the difficulties they are going through. The opportunity is there for the schools to provide their teachers and support workers with the resources and training that is needed. Advocacy is key! Parents need to advocate for their child and ensure that schools are working with them to provide for their child. The stigma they endure, along with other feelings of shame, racism and prejudice, needs to be addressed as well.

Recognizing how intergenerational trauma, residential schooling, and mental health factor into the perceptions that one has of parents and Indigenous children with FASD is crucial. After reading the literature, as well as reviewing the narratives given by the participants, I noticed a lack of support that nurtured from a variety of factors, such as lack of knowledge, misunderstanding, lack of desire. There is a need to educate, advocate, and support these parents, not only with supporting their child at school but also supporting them with self-care and respite. All six participants gave a number of

recommendations for other parents. These recommendations all support the need to educate oneself, advocate for their child and take care of themselves. These recommendations should be part of their daily life, not something that they must fight for to get. Parenting a child can be stressful at times but when the discombobulation of FASD is added into the circle, the lack of support, undue stress, and stigma can have an adverse effect on these parents.

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Appendix A: Interview Guide

Research question	Interview questions
RQ: How do parents of Indigenous school-aged children with FASD describe their experience with school personnel?	<p>IQ1: Tell me about your experience being pregnant with your child.</p> <p>Follow-up Question</p> <p>1a: When did you first notice that your child had a disability?</p>
	<p>IQ2: Tell me about your personal experiences on receiving a diagnosis for your child.</p> <p>Follow-up Questions</p> <p>2a: How were you able to find the proper services for your child?</p> <p>2b: How long did it take you to get a diagnosis?</p> <p>2c: How did you feel about the diagnosis?</p> <p>2d: Have you experienced any bias in your child's diagnosis of FASD?</p> <p>2e: How did you go about getting information about FASD once your child was diagnosed?</p>
	<p>IQ3: Has there been a history of FASD in your family?</p> <p>Follow-up Question</p> <p>3a: Have you had any experience or knowledge of FASD before your child's diagnosis?</p>

IQ4: What kinds of support are in place for your child?

Follow-up Questions

4a: What type of professional help has been put in place for your child?

4b: What kinds of government funding/programs have been made available to you and your family to help support your child?

IQ 5: What have the teachers done at your school to help you make your child's adjustment to the classroom a smooth process?

Follow-up Question

5a: How had these experiences at school made you feel?

IQ 6: How did you feel about your child's first experience at school after his/her diagnosis?

IQ 7: How did the other children act towards your child?

Follow-up Question

7a: Has your child experienced any bullying from other children at school?

7b: If so, can you tell me about it.

IQ 8: Do you feel that the school personnel treated you differently because of your child's diagnosis?

Follow-up Question

8a: What challenges did you meet from the school personnel?

IQ 9: Tell me about any experiences of your child being treated differently because of his/her diagnosis you may have encountered.

Follow-up Question

9a: Can you tell me if there was ever a time your child experienced being singled out in the classroom?

IQ 10: Tell me about any incidents of blame or stressful events that you may have experienced with school personnel.

IQ 11: What suggestions/advice do you have for other parents of children with FASD?
