Overcoming Adversity: The Stories of Four Resilient Adults with Fetal Alcohol Spectrum Disorders

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ABSTRACT

The present study explored the school and life experiences of four individuals, between the ages of 19-30, who were diagnosed with a Fetal Alcohol Spectrum Disorder (FASD). Semi-structured interviews provided insight into the lives of these adults. Their experiences with this disorder as it relates to their social interactions and peer relationships in the community, elementary, and high school, were explored. Merriam's (2002) basic qualitative approach was utilized to explore the experiences of these individuals. A definitional focus on resiliency remained present when analyzing data generated through the interviews. Their educational and life experiences were examined with the goal of understanding how success is achieved among these individuals. Three major themes emerged from participant interviews: (1) "I don't fit in": negative school experiences lead to anger and frustration toward diagnosis; (2) intergenerational alcoholism, child abuse, and drug addiction; and (3) healing the wounds: sources of strength, success and helping others. Despite the hardships these participants faced, they each found sources of strength and success that have allowed them to be resilient in the face of adversity. These sources of strength and success are considered in connection with existing research literature. Practical implications of the findings, the limitations and strengths of the current study, and areas for future research are discussed.

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Finally, to my mom, thank you for your unwavering love and encouragement throughout my many years at university. I would not have made it this far without your support. Your modeling of hard work and words of wisdom have had a tremendous influence on my achievements thus far in life. You always told me to work hard and get an education so that I could be self-sufficient and I thank you for instilling in me this strong work ethic. I am, without a doubt, the person I am today because of you.

DEDICATION

This thesis is dedicated to my sister, her children,
the individuals who shared their experiences in this study,
and to all those who are or know someone diagnosed with a FASD.
May the information discussed here prove helpful in some way.

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CHAPTER 1: INTRODUCTION

My personal interest in Fetal Alcohol Spectrum Disorders (FASDs) began approximately four years ago when my sister first revealed a long held secret. I grew up in a small community in rural Saskatchewan with my two older siblings who were both adopted. My brother is 14 years my senior and my sister is 13 years older than I. When my parents adopted my sister it appeared in her birth records that my sisters' mother had drank alcohol while she was pregnant. However, in 1974 the direct connection between prenatal alcohol consumption and the significant effects on the fetus were not completely understood. My parents did not give a second thought to this matter and they decided on adoption.

I always knew my sister had trouble in school and did not get along very well with my mom, but I did not realize why until she had children of her own. When I was eight years old I became an auntie to my sisters' first-born son who I will call David. A year later I became an auntie a second time when she had a little girl who I will call Melissa. It was not until many years later that my sister finally admitted that she drank while she was pregnant with both of her children. David was diagnosed with partial Fetal Alcohol Syndrome (partial FAS) and Melissa with Alcohol-Related Neurodevelopmental Disorder (ARND). I was around nineteen years old at this time and I knew very little about Fetal Alcohol Spectrum Disorders (FASDs). I soon became interested in learning about Fetal Alcohol Spectrum Disorders so I could help my own family have a better understanding as to why my sister and her children often displayed certain behaviours. I use my knowledge to educate my family about FASDs in hopes that they will educate others and stop the cycle of this disorder within our family. I am deeply connected to FASD due to my experiences. Thus, I hope my research can contribute knowledge and improve understanding for those affected by this disorder, as well as the members of their support systems, and those who work with individuals who are prenatally exposed to alcohol. Before these personal connections can be further explored and discussed, the current situation regarding FASDs must be considered.

Prenatal alcohol consumption is known to adversely affect the unborn child, resulting in a range of lifelong developmental disabilities and hardships (Connor & Streissguth, 1996). These disabilities not only affect the individual, but also the family, community, and all of society (Chudley et al., 2005; Saskatchewan Learning, 2004). Parents of children with FASD often struggle with their children's numerous behaviour problems, keeping the children involved in

social activities, and collaborating with school personnel (Brown & Bednar, 2004). Fetal Alcohol Spectrum Disorders (FASDs) are the leading known cause of developmental disabilities within Canada (Public Health Agency of Canada, 2008). Direct costs associated with FASDs have been estimated at $1.5 million per person across a lifetime, (Public Health Agency of Canada, 2005) including direct health, social, and justice system costs and the indirect costs related to mortality, disability, and incarceration (Ryan, Bonnett, & Gass, 2006). Although difficult to accurately estimate, it is projected that 9 out of every 1,000 babies are born with FASDs in Canada each year (Public Health Agency of Canada, 2005). In some high-risk communities (i.e., First Nation and Inuit populations, rural areas, and isolated northern communities), given the history of colonization and devaluation of culture, the rates may be as high as 1 in 5 (Health Canada, 2001; Public Health Agency of Canada, 2005). Within Canada it is estimated that each year, over 3,000 babies are born with FASDs and around 300,000 more people are currently living with this disorder (Health Canada, 2006). In light of this high prevalence rate, it is important that the experiences of individuals with FASDs are expressed and understood.

The range of effects caused by prenatal alcohol exposure varies among individuals, but it is generally characterized by primary disabilities in: executive functioning (i.e., planning and abstract thinking; Connor, Sampon, Bookstein, Barr, & Streissguth, 2000); cognitive capacity (Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998); memory and behaviour (Streissguth, 2007); social skills (McGee, Fryer, Bjorkquist, Mattson, & Riley, 2009); and impulse control (Connor et al., 2000; Streissguth, 2007). Individuals with FASDs also exhibit secondary disabilities, which occur after birth and are direct manifestations of primary disabilities (e.g., mental health problems; inappropriate sexual behaviours; disrupted school experience; and trouble with the law; Government of Canada, 2007; Saskatchewan Learning, 2004). These difficulties hinder the ability of individuals with FASDs to behave in socially acceptable ways and, therefore, discourage the successful formation of positive peer relationships (Kelly, Day, & Streissguth, 2000; Thomas, Kelly, Mattson, & Riley, 1998).

Much of the existing research concerning prenatal alcohol exposure has been quantitative in nature (e.g., Bishop, Gahagan & Lord, 2007; Frankel, Paley, Marquardt & O'Connor, 2006; McGee, Bjorkquist, Price, Mattson & Riley, 2009; O'Connor et al., 2006; Rasmussen & Bisanz, 2008; Schonfeld, Paley, Frankel & O'Connor, 2006; Schonfeld, Paley, Frankel & O'Connor,

2008). However, a limited number of studies have focused on the perspectives and experiences of the individuals who have actually been diagnosed with a FASD. For example, Ryan and Ferguson (2006) explored the diagnostic process and the experiences of professionals and families members associated with five Alaskan students with a Fetal Alcohol Spectrum Disorder. Although these researchers did not interview the students with FASD directly, more than 400 hours were spent observing the students in their homes, in school or treatment facilities, and during different activities (Ryan & Ferguson, 2006). They found: (1) despite an increase in public awareness, limited services exist for children diagnosed with FASDs and their families; (2) beginning teachers are less likely to adapt instruction for students with FASDs, while experienced teachers use differentiated instruction more readily; and (3) there is a persistent impact of challenging behaviours, but limited support provided to families (Ryan & Ferguson, 2006). Massey (1997) used hermeneutic phenomenology to explore the lives of five women between the ages of 18 and 30, who had been diagnosed with either FAS (Fetal Alcohol Syndrome) or FAE (Fetal Alcohol Effects). Themes of poverty, unemployment, prostitution, alcohol and substance abuse, sexual abuse, pregnancy, suicide, isolation, and inequality were experienced among the five women in the study (Massey, 1997). In another qualitative study, Duquette, Stodel, Fullarton, and Hagglund (2006) used collective case studies to examine the reason behind persistence in high school among students with FASDs, from the adolescents' perspectives. They found persistence in high school was largely due to the strong support and advocacy provided by the participants' adoptive parents. In another study by Duquette and Stodel (2005) they examined the educational experiences of individuals with Fetal Alcohol Spectrum Disorders and what contributed to a successful school experience. Participants included eleven parents and seven children who spoke about their school experiences. Data was collected through questionnaires and semi-structured interviews. There were five elements that participants identified as contributing to a successful school experience: caring teachers, appropriate programs and services, obtaining a medical diagnosis, supportive parents, and the transition to adult life. It is apparent by the research presented above that there is a lack of research on the educational and life experiences of individuals diagnosed with Fetal Alcohol Spectrum Disorders. Although numerous studies have focused on the impairments individuals with FASDs encounter and how this can lead to difficulty in school (Coles, Lynch, Kable, Johnson, & Goldstein, 2010; Olson, Streissguth, Sampson, Barr, Bookstein, & Thiede, 1997;

Riley & McGee, 2005; Rasmussen & Bisanz, 2009; Stuss & Knight, 2002). Little is known about the school and life experiences of those with FASDs. In order to develop appropriate programs and accommodations that will help these individuals experience success in school and life, it is necessary that we examine the experiences of those with FASDs directly from their perspectives.

1.1 Statement of Purpose

More information is needed to better understand how individuals with FASDs believe prenatal alcohol exposure has affected their school and life experiences. In order to reduce the costs of FASDs on Canadian society, and expand educators' understanding and ability to address students' needs, effective interventions need to be based on the educational and individual needs of those diagnosed with FASDs. Currently, there are a limited number of interventions used to help individuals prenatally exposed to alcohol with the particular problems they experience (e.g., communication and language difficulties; Peadon, Rhys-Jones, Bower & Elliott, 2009). Therefore, the aim of this study was to further contribute to this small body of research by seeking the perspectives of those who have been prenatally exposed to alcohol. Identifying their direct needs may allow educators, parents, and all those who work and care for individuals with FASDs to begin to address and improve their outcomes in life. By presenting their experiences in their own words, the participants have provided valuable information. The current study focused on the experiences of four adults who were diagnosed with a specific Fetal Alcohol Spectrum Disorder. The purpose of the study was to describe and understand their experiences, with the hopes of coming to a greater understanding of how success is achieved among these individuals. The research questions that guided this inquiry were: (1) What are the school and life experiences of those diagnosed with Fetal Alcohol Spectrum Disorders? and (2) What has allowed these individuals to achieve success in school and life situations?

1.2 Definitions

For the purpose of adding greater clarity to this study, the following terms will be defined:

1.2.1 Fetal alcohol spectrum disorder. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to collectively refer to the wide range of effects caused by the consumption of alcohol during pregnancy (Chudley et al., 2005; Ryan, Bonnett, & Gass, 2006; Saskatchewan Learning, 2004). These effects differ in each individual but often include some form of physical,

mental, behavioural, and learning disabilities which persist into adulthood and therefore have varying impacts across the lifespan (Chudley et al., 2005). The term FASD is not a diagnostic term but instead refers to the spectrum of disorders that are caused by the maternal consumption of alcohol (Chudley et al., 2005). Three diagnostic categories exist within the umbrella term: Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (partial FAS), and Alcohol-Related Neurodevelopmental Disorder (ARND, Chudley et al., 2005). Each category displays its own set of associated characteristics (Chudley et al., 2005).

1.2.2 Fetal alcohol syndrome. A diagnosis of Fetal Alcohol Syndrome (FAS) is given when the individual displays evidence of facial abnormalities (e.g., smooth or flattened philtrum, which is the space between your upper lip and nose), growth retardation (e.g., height or weight at or below the 10th percentile for age), and central nervous system damage (e.g., impairment in executive functioning and abstract reasoning) with confirmed (or unconfirmed) maternal alcohol exposure (Chudley et al., 2005; Green, 2007; Saskatchewan Learning, 2004).

1.2.3 Partial fetal alcohol syndrome. Partial Fetal Alcohol Syndrome (partial FAS) describes an individual who displays some, but not all of the facial abnormalities associated with FAS, and evidence of central nervous system damage with a confirmed history of maternal alcohol exposure (Chudley et al., 2005). For prenatal alcohol exposure to be confirmed, maternal alcohol consumption during the pregnancy in question must be established through either of the following ways: "based on reliable clinical observation, self report, reports by a reliable source or medical records documenting positive blood alcohol, alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy" (Chudley et al., 2005, p. S11). Word of mouth reports, lifestyle factors, other drug use, or a history of alcohol use in previous pregnancies cannot be used to confirm alcohol exposure during the pregnancy in question (Chudley et al., 2005).

1.2.4 Alcohol-related neurodevelopmental disorder. The final diagnostic category under the umbrella of FASD is known as Alcohol-Related Neurodevelopmental Disorder (ARND). This diagnosis is used to describe an individual who has central nervous system damage and/or a complex pattern of behavioural or cognitive impairments (e.g., deficit in communication, academic achievement, memory, executive functioning and abstract reasoning, social skills and social communication) that are inconsistent with one's developmental stage (Saskatchewan Learning, 2004; Stratton, Howe, & Battaglia, 1996). Again, a confirmed history

of prenatal alcohol exposure must exist in order to make this diagnosis (Stratton, Howe, & Battaglia, 1996).

1.3 Significance of the Study

There are several reasons why this study is significant. First, it provides insight and understanding into the lives of individuals affected with FASDs. Knowledge related to how their diagnosis affects their school and life experiences, social interactions, peer interactions, and how they cope with this disorder is under studied and therefore was explored within the current study. Second, this research has the potential to provide educators with information to ensure that adolescents and children prenatally exposed to alcohol are provided with appropriate and nurturing educational experiences. Professionals who employ intervention strategies with these individuals often do so with a limited understanding of what interventions these individuals have found to be most effective. Lastly, and most important, few previous studies have focused on understanding the school and life experiences directly from the individuals themselves. Therefore, the current study aimed to contribute to this small body of research and provide a more comprehensive understanding of this disorder.

1.4 Chapter Organization

A review of the literature related to Fetal Alcohol Spectrum Disorders follows in Chapter 2; then a description of the research methods and procedures employed is provided in Chapter 3. Chapter 4 presents the results of the study and the three major themes that were found. Finally, Chapter 5 discusses the integration of the findings to existing literature, strengths and limitations of the current study, and implications for future research.

CHAPTER 2: LITERATURE REVIEW

The review of the literature related to Fetal Alcohol Spectrum Disorders is divided into five major sections. Section one discusses the history of Fetal Alcohol Spectrum Disorders. Section two focuses on the early and current diagnostic criteria related to FAS, partial FAS, and ARND. Section three examines the prevalence of FASDs within Canada, while section four reviews the major effects prenatal alcohol exposure has on the brain and the subsequent effects on behaviour, memory, communication, cognitive functioning and social skills. Finally, section five discusses research related to resiliency in those diagnosed with Fetal Alcohol Spectrum Disorders.

2.1 The History of Fetal Alcohol Spectrum Disorders

Although many consider Fetal Alcohol Spectrum Disorder to be a relatively new phenomenon, the relationship between prenatal alcohol exposure and undesirable birth defects has been noted for centuries (Calhoun & Warren, 2007). One of the earliest references to the effects of prenatal alcohol exposure is an ancient Greek and Roman belief that maternal alcohol intoxication resulted in the birth of a deformed child (Jones & Smith, 1973). The Bible also has several passages that urge women to cease from drinking wine during pregnancy (Massey, 1997). However, some reviewers have pointed out that in ancient Greece and Rome the belief was not that drinking during pregnancy harmed the child, but that being intoxicated at the moment of conception led to deformity (Calhoun & Warren, 2007).

Articles in leading scientific and medical journals during the 1940s to the 1960s, upheld the eugenics theory on the effects of alcohol on prenatal development (Massey, 1997). Those who upheld the eugenics theory essentially believed that those who were *fit* should be encouraged to reproduce and those who were *unfit* should be prevented from doing so (Rafter, 1992). It was believed the abnormalities seen in children whose mothers drank during pregnancy were the result of genetic defects and not prenatal alcohol exposure. It was not until 1968 that a French research team consisting of Lemoine, Harousseau, Borteyru, and Menuet first described in detail the serious physical effects of alcohol consumption on the fetus (Lemoine et al., 1968; Lemoine et al., 2003). Lemoine et al. (1968) stated the many physical abnormalities that often appeared in children whose mother consumed alcohol during pregnancy. These effects included: miscarriages, stillbirths, prematurity, growth retardation, psycho-somatic alterations with very specific facial features, and malformations. However, no diagnostic guidelines for Fetal Alcohol

Spectrum Disorders were identified (Green, 2008; Lemoine, 1968). Unfortunately, the publication of this paper was met with skepticism and had little to no effect on the public's general opinion of drinking during pregnancy (Calhoun & Warren, 2007).

Five years later, Jones, Smith, Ulleland, and Streissguth (1973) identified a pattern of "craniofacial, limb, and cardiovascular defects associated with prenatal-onset growth deficiency and development delay" in eight unrelated children of three ethnic groups, all born to mothers who drank during pregnancy (p. 1267). Later that same year, Jones and Smith (1973) coined the term *Fetal Alcohol Syndrome* (FAS) and made the first steps towards a clinical diagnosis of FAS. This work was the first to seriously influence people's opinions on the harmful effects of prenatal alcohol consumption on the unborn fetus (Massey, 1997).

To date there have been hundreds of studies throughout the world documenting the serious risks and consequences associated with consuming alcohol during pregnancy (Niccols, 2007). While Jones and Smith's (1973) publication focused on extreme conditions of prenatal alcohol exposure, their discoveries set the foundation for our current diagnostic guidelines (i.e., the characteristic facial abnormalities, growth retardation, and central nervous system dysfunction; Green, 2008). Diagnostic criteria have now been created to provide physicians with a tool to assist in the diagnosis of FASDs (Stoler & Holmes, 2004). The early and current methods for making a diagnosis of the specific Fetal Alcohol Spectrum Disorders can now be considered.

2.2 Diagnosis

2.2.1 Early diagnostic criteria. Jones and Smith (1973) first outlined the early diagnostic guidelines for Fetal Alcohol Syndrome (e.g., craniofacial, limb and cardiovascular defects associated with prenatal-onset growth deficiency and developmental delay; Green, 2008). However, these guidelines did not become readily adopted into the community of researchers and medical professionals until 1975 when greater detail was provided (Green, 2008). Jones and Smith (1973) described the distinguishing features of FAS and provided pictures of children with prenatal alcohol exposure from three different ethnicities. The first autopsy of a child with FAS was also described in this paper, which revealed widespread damage throughout much of the brain (Jones & Smith, 1973). Clarren and Smith (1978) further described the characteristic features associated with FAS in great detail. They made reference to the wide array of adverse effects that prenatal alcohol consumption can have on the developing fetus. The malformations

associated with prenatal alcohol exposure were placed into four different categories: central nervous system damage, growth deficiencies, facial deformities, and variable major and minor abnormalities (Clarren & Smith, 1978). For a diagnosis of FAS to be given, individuals had to have differences in three of the four categories (Clarren & Smith, 1978). Those individuals that had two of the four diagnostic criteria were identified as having *suspected fetal alcohol effects* (FAE; Clarren & Smith, 1978).

While the guidelines provided by Clarren and Smith (1978) added greater clarity to the existing diagnostic criteria by presenting the four major categories, the need for further research in this area was necessary (Green, 2008). In 1980, this issue was addressed by the Fetal Alcohol Study Group of the Research Society on Alcoholism (RSA) when they developed a standardized set of diagnostic criteria for FAS (Rosett, 1980). The Fetal Alcohol Study Group of the RSA was composed of physicians, clinical psychologists as well as experimentalists trained in basic research (Rosett, 1980). Based on a review of 245 case reports by Clarren and Smith (1978), they suggested a diagnosis of FAS be made when an individual exhibits signs in each of the following three categories: 1) prenatal and/or postnatal growth retardation (weight, length, and/or head circumference below the 10th percentile when corrected for age); 2) central nervous system damage (signs of neurological abnormality, developmental delay, or intellectual impairment); and 3) characteristic facial deformities with at least two of three signs: microcephaly (head circumference below the 3rd percentile), microophthalmia and/or short palpebral fissures, or poorly developed philtrums, thin upper lip, and flattening of the maxillary area (Rosett, 1980). The Fetal Alcohol Study group decided that due to the wide spectrum of effects, individuals should receive a diagnosis of FAS when displaying all three diagnostic features and *possible fetal alcohol effects* in the absence of all three (Rosett, 1980). However, the Fetal Alcohol Study group did not explore the number of criteria that needed to be present for a diagnosis of *possible fetal alcohol effects* to be given. Since this time, diagnostic guidelines have continued to become increasingly rigorous and more specific.

2.2.2 Current diagnostic criteria. Diagnostic guidelines have improved immensely since the first reported cases of maternal alcohol consumption linked to birth defects. Currently, five sets of guidelines to aid in the diagnosis of FASDs are used throughout the world (Green, 2008). These include: the Institute of Medicine (IOM) FASD guidelines (Stratton et al., 1996), the four-digit FASD Diagnostic Code (Astley & Clarren, 2000), Centers for Disease Control and

Prevention FAS guidelines (Centers for Disease Control and Prevention, 2004), the Canadian guidelines for FASD diagnoses (Chudley et al., 2005), and the revised Institute of Medicine FASD guidelines of 1996 (Hoyme et al., 2005). For the purposes of this research, the FASD diagnostic criteria presented by Chudley et al., (2005) will be used and explored in greater detail due to its focus on Canadian guidelines.

In 2005, a subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder examined, evaluated, and incorporated current diagnostic criteria to form standard Canadian guidelines (Chudley et al., 2005). The Canadian guidelines use a combination of the IOM guidelines and the four-digit diagnostic code (Chudley et al., 2005). The four-digit diagnostic code is used to describe, assess, and measure alcohol exposure, growth, facial features and brain damage (Green, 2008). The terminology in the IOM guidelines is used (FAS with and without maternal alcohol exposure, partial FAS with confirmed maternal alcohol exposure, and Alcohol-Related Neurodevelopmental Disorder) with the exception of the Alcohol-Related Birth Defects (ARBD) category (Chudley et al., 2005; Green, 2008). ARBD consists of a list of congenital abnormalities, including cardiac (e.g., ventricular septal defects), skeletal (e.g., shortened fifth digits), renal (e.g., horseshoe kidneys), ocular (e.g., retinal vascular anomalies), auditory (e.g., conductive hearing loss) and other malformations (Chudley et al., 2005). The category of ARBD was removed due to its limited diagnostic utility and should therefore be used with caution (Chudley et al., 2005).

A variety of diagnostic terminology is used within Canada. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to collectively refer to the range of effects caused by the maternal consumption of alcohol during pregnancy (Chudley et al., 2005; Ryan, Bonnett, & Gass, 2006; Saskatchewan Learning, 2004). However, the term FASD is not to be used as a diagnostic term, but to refer to the spectrum of physical, mental, behavioural, and learning disabilities that are caused by prenatal alcohol exposure (Chudley et al., 2005). Three diagnostic categories exist within the umbrella term with each category displaying its own set of associated characteristics (Chudley et al., 2005).

2.2.3 Fetal alcohol syndrome. A diagnosis of Fetal Alcohol Syndrome (FAS) is given when the individual displays evidence of growth retardation, facial abnormalities, and central nervous system damage (Green, 2007; Saskatchewan Learning, 2004). A diagnosis can be made with or without confirmed maternal alcohol exposure when the individual meets the diagnostic

criteria for FAS (Chudley et al., 2005). The diagnostic criteria for fetal alcohol syndrome are A) prenatal or postnatal growth deficiency as revealed by at least one of the following: 1) birth weight or birth length at or below the 10th percentile for gestational age, 2) height or weight at or below the 10th percentile for age, or 3) disproportionately low weight-to-height ratio (= 10th percentile) (Chudley et al., 2005). The individual must also meet the second diagnostic criteria which includes B) simultaneously having all three of the following facial abnormalities at any age: 1) short palpebral fissures (i.e. short horizontal length of eyes), 2) smooth or flattened philtrum (i.e. the space between the upper lip and nose), and 3) thin upper lip (Chudley et al., 2005). However, alcohol exposure during pregnancy affects the natural development of not only the individual's height, weight, philtrum, eyes, and lips, but most importantly the brain (Green, 2007). The brain damage that occurs can have a wide range of effects on the individual (Green, 2007) and these effects are explained further in the third diagnostic criteria. An individual must display C) impairment in three or more of the following central nervous system areas: hard and soft neurological signs, brain structure, cognition, communication, academic achievement, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity, adaptive behaviour, social skills, and social communication (Chudley et al., 2005). While the diagnostic criteria for FAS are relatively clear and uncomplicated, the identification and subsequent diagnosis of other FASDs is more difficult and less straightforward (Green, 2007).

2.2.4 Partial fetal alcohol syndrome. Partial Fetal Alcohol Syndrome (partial FAS) describes an individual who displays some, but not all of the facial abnormalities associated with FAS, and evidence of central nervous system damage with a confirmed history of maternal alcohol exposure (Chudley et al., 2005). More specifically, the diagnostic criteria for partial Fetal Alcohol Syndrome includes: A) concurrent appearance of two of the following facial abnormalities at any age: 1) short palpebral fissures, 2) smooth or flattened philtrum, and a 3) thin upper lip (Chudley et al., 2005). Secondly, there must also be evidence of B) impairment in three or more of the following central nervous system areas: hard and soft neurological signs, brain structure, cognition, communication, academic achievement, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity, adaptive behaviour, social skills and social communication (Chudley et al., 2005). Lastly, in order for prenatal alcohol exposure to be confirmed, maternal alcohol consumption during the pregnancy must be established (Chudley et al., 2005). Evidence of maternal alcohol consumption can be obtained in

the following ways: through a reliable clinical observation, self report, reports by a reliable source, medical records documenting positive blood alcohol levels, and alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy (Chudley et al., 2005). Word of mouth reports, knowledge of lifestyle, other drug use, or a history of alcohol use in previous pregnancies cannot, by themselves, confirm alcohol exposure for the pregnancy in question (Chudley et al., 2005).

It is important to realize that the term *partial* in partial FAS does not imply that these individuals are less impaired in everyday functioning than those with a FAS diagnosis (Chudley et al., 2005; Green, 2007). Individuals with partial FAS often demonstrate the same cognitive, social, emotional, and behavioural difficulties associated with FAS (Chudley et al., 2005; Green, 2007). However, because not all individuals prenatally exposed to alcohol have the characteristic facial features associated with FAS or they may be less pronounced, many of them go undiagnosed and often without proper support (Green, 2007). The same is true for Alcohol-Related Neurodevelopmental Disorder, which is the next and last diagnostic term to be discussed.

2.2.5 Alcohol-related neurodevelopmental disorder. The final diagnostic category under the umbrella of FASD is known as Alcohol-Related Neurodevelopmental Disorder (ARND). A diagnosis of ARND is given when the individual exhibits evidence of impairment in three or more of the following central nervous system areas: hard and soft neurological signs, brain structure, cognition, communication, academic achievement, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity, adaptive behaviour, social skills, and social communication (Chudley et al., 2005). The impairments of the central nervous system may be manifested in poor school performance, lack of abstract thinking, limited impulse control, deficits in language and math skills, and finally problems with memory, attention and judgment (Saskatchewan Learning, 2004). Again, confirmed maternal alcohol exposure is required in order to make a diagnosis of ARND (Chudley et al., 2005). To date, the criteria for diagnoses of ARND are not as objectively defined or acknowledged compared to the criteria for FAS (Green, 2007). This also creates a problem for determining incidence and prevalence rates of FASDs throughout Canada and the rest of the world when diagnostic criteria are not explicitly defined.

2.3 Prevalence of FASDs within Canada

It is extremely difficult to accurately establish the prevalence of FASDs since there are no biological markers that can accurately identify those who are affected (Sokol, Delaney & Nordstrom, 2003). Therefore, the numbers likely underestimate actual prevalence rates seen around the world (Sokol, Delaney & Nordstrom, 2003). However, it is projected that 9 out of every 1,000 babies are born with FASDs in Canada each year (Public Health Agency of Canada, 2003). Previous studies have found varying prevalence rates in different parts of the country; (e.g., 46 per 1000 births in the Yukon, 26 per 1000 in B.C. and .5-.6 per 1000 live births in Saskatchewan) since prevalence is related to the frequency of excessive alcohol use in pregnancy it will therefore vary based on the population studied (Chudley, Kilgour, Cranston & Edwards, 2007).

The reasons for these variable rates in prevalence are related to numerous factors which include: differing poverty rates between provinces (poverty is strongly associated with alcohol use before and during pregnancy), genetic and ethnic differences, lack of uniformly accepted diagnostic criteria for FASDs in the past, and lack of knowledge, skill, training, and misconceptions among care givers (CDC, 2005). Also some of the variability in prevalence rates reflects different patterns of alcohol use and abuse in different areas of the country (Williams, Odaibo & McGee, 1999). However, there are also numerous methodological issues affecting the prevalence rates (Williams, Odaibo, & McGee, 1999). Williams, Odaibo, and McGee (1999) argued that prevalence studies that solely rely on birth records tend to underestimate rates due to the fact that problems associated with central nervous system damage are often not visible until the children are older. For example, Habbick, Nanson, Snyder et al. (1996) estimated the prevalence of FAS in Saskatchewan to be .5 per 1000 live births in 1973-1977 and .6 per 1000 births in 1988 to 1992. Also studies that base their rates exclusively on children who are referred for a FAS assessment may miss those children who lack facial characteristics like those with partial FAS and Alcohol-Related Neurodevelopmental Disorder (Williams, Odaibo, & McGee, 1999). Asante and Nelms-Matzke (1985) conducted a study of aboriginal groups in the Yukon and northern British Columbia and found a FAS prevalence rate of 46 per 1000 births in the Yukon and 26 per 1000 in British Columbia. Other studies that perform assessments on all children in one particular area often produce higher prevalence rates because they have specifically chosen sites where FASDs are thought to occur more often (Williams, Odaibo, &

McGee, 1999). For example, a study of an isolated aboriginal community in British Columbia found rates of FASDs to be as high as 190 per 1000 live births (Robinson, Conry, & Conry, 1987). In a Manitoba First Nations community, the prevalence of FAS and partial FAS was found to be 55-101 per 1000 births (Square, 1997). While, a study that focused on a different community in northeastern Manitoba found a prevalence of about 7.2 per 1000 live births (Williams, Odaibo & McGee, 1999). Therefore, it is extremely important when examining prevalence studies to understand exactly how researchers found the numbers that appear within their study.

Now that a better understanding of the history, diagnostic criteria, and prevalence rates of FASDs have been established, some of the many effects prenatal alcohol exposure can have on the individual will be considered. This will allow for a deeper understanding of those affected by prenatal alcohol exposure and the many changes that occur in their brain. These neurological changes are then reflected in their behaviour, communication, academic performance, social interactions and relationships, and cognitive functioning.

2.4 The Effects of Prenatal Alcohol Exposure

The impact of alcohol on the fetus varies with the amount, stage of embryological development, and frequency with which the alcohol is consumed (Health Canada, 2003; Niccols, 2007). At the time of conception and during the first few weeks of prenatal development, the alcohol may act as a cytotoxic or mutating substance, which will either lead to cell death or chromosomal alterations (Niccols, 2007). It is important to note that this damage could occur before a woman even realizes she is pregnant (Niccols, 2007). Around four to ten weeks after conception, alcohol begins to cause excessive cell death in the central nervous system and abnormalities in cell migration (Niccols, 2007). In the third trimester, alcohol exposure causes damage to the cerebellum, hippocampus, and prefrontal cortex (Niccols, 2007). These biological malformations may be the reason for the behavioural problems and neurological deficits seen in individuals with FASDs (Niccols, 2007). Thus, the pattern of defects seen will vary depending on which stage of development the fetus was in when the alcohol was consumed.

Still, a number of other factors also determine the outcome of prenatal alcohol exposure including: the genetics of the fetus and mother, the overall health of the mother, as well as the many social, economic, physical and environmental factors such as socioeconomic status and synergistic reactions with other drugs (Health Canada, 2003; Riley & McGee, 2005). Nutritional

factors also influence blood alcohol levels and therefore determine the effect the alcohol will have on the developing fetus (Riley & McGee, 2005). Age of the mother is another factor that has been determined as an important risk factor for developing FAS, with infants of mothers over thirty at a higher risk than those of younger mothers (Jacobson, Jacobson, Sokol, Chiodo, & Corobana, 2004; Riley & McGee, 2005). Thus, it should not be surprising that different individuals exposed to the same amount of alcohol during pregnancy have differing outcomes (Riley & McGee, 2005). Whereas some individuals are severely affected in multiple areas, others may have mild to no apparent effects (Riley & McGee, 2005).

Exposure to lower levels of alcohol often emerges as problems in behaviour and adaptive functioning (Olson, Streissguth, Sampson, Barr, Bookstein, & Thiede, 1997). The greater the prenatal alcohol exposure the greater the developmental deficits and the more likely that physical and structural abnormalities in the brain will occur (Vorhees & Mollnow, 1987). These structural brain abnormalities may be manifested through immature social and reasoning skills, difficulty generalizing information from one situation to another, memory problems, impulsive and hyperactive behaviour, distractibility, difficulty processing sensory information, poor fine and gross motor skills, difficulty understanding the consequences of actions, and the display of poor planning and listening skills (Government of Canada, 2007; Green, 2007; Saskatchewan Learning, 2004). These challenges are also known as primary disabilities (Government of Canada, 2007). Primary disabilities are those that the individual was born with and they are the direct result of the neurological damage caused by prenatal alcohol exposure (Government of Canada, 2007). It is important to recognize that all primary disabilities greatly affect an individual's potential for learning (Saskatchewan Learning, 2004).

Individuals with prenatal alcohol exposure also display secondary disabilities; these are disabilities that the individual was not born with and can be improved through better understanding and appropriate interventions (Chudley et al., 2007; Government of Canada, 2007). Streissguth, Barr, Kogan and Bookstein (1997) state that secondary disabilities are the result of an interaction between behavioural and mental health problems combined with an undesirable environment. Secondary disabilities that apply to individuals of all ages may include: mental health problems, disrupted school experience, trouble with the law, incarceration, inappropriate sexual behaviour, alcohol and drug problems, and difficulty handling money (Government of Canada, 2007; Saskatchewan Learning, 2004; Streissguth et al., 1997).

Three secondary disabilities including: dependent living, issues with employment, and problems with parenting are common in older adolescents and adults with prenatal alcohol exposure (Streissguth et al., 1997). Other common secondary disabilities may include "depression, anxiety, sexual promiscuity, poor judgment, poor impulse control, restlessness, poor problem solving skills, resistance to change, difficulty forming lasting and meaningful relationships, gullibility and victimization, inability to understand or conform to social norms and unemployment" (Chudley et al., p. 262, 2007).

2.4.1 Changes in brain structure. Although the pattern of facial abnormalities seen in individuals with FAS is the most obvious sign of heavy prenatal alcohol exposure, the most devastating effects are related to the changes seen in the brain and behaviour (Riley & McGee, 2005). The remainder of this overview will focus on the changes that take place in the brain, which have the greatest impact on the individuals affected by prenatal alcohol exposure.

Jones and Smith (1975) described the results of an autopsy preformed on an infant with FAS, this revealed extensive damage throughout many areas of the brain. The infant had a small brain that was completely missing the corpus callosum, which is a brain structure that allows communication to occur between the two hemispheres of the brain (Jones & Smith, 1975). During normal embryo development, the nerve cells migrate to their appropriate positions in the brain (Mattson, Jernigan & Riley, 1994). However, in this infant, the autopsy revealed cells throughout the brain tissue which had migrated to inappropriate places (Jones & Smith, 1975). More recently, research using magnetic resonance imaging (MRI) has revealed specific abnormalities in the brains of living individuals both with and without a diagnosis of FAS (Riley & McGee, 2005). Since 1992, Riley and McGee's (2005) laboratory in San Diego has been conducting MRI studies of children with FASDs. Recent technological advancements in image analysis techniques have provided new insights into the damage caused by prenatal alcohol exposure (Riley & McGee, 2005).

2.4.1.1 Brain size. MRI studies consistently reveal reductions in brain size of individuals exposed to alcohol prenatally (Archibald et al., 2001; Johnson, Swayze, Sato, & Andreasen, 1996; Mattson, Jernigan, & Riley, 1994). However, not all areas of the brain are equally affected, Archibald et al., (2001) found only the parietal lobe was reduced in size when the overall brain size was taken into account. Another study also found reduced brain growth in the frontal lobes of the individuals prenatally exposed to alcohol, these growth deficiencies were

most pronounced in the left hemisphere (Sowell et al., 2002). These results are consistent with the findings in the literature that are related to cognitive and behavioural aspects of functioning, which reports that children with prenatal alcohol exposure have difficulties with response inhibition, behaviour control, and executive functioning (Connor et al., 2000; Streissguth, 2007).

2.4.1.2 Corpus callosum and basal ganglia. Both the corpus callosum and the basal ganglia are particularly sensitive to the effects of prenatal alcohol exposure (Riley & McGee, 2005). Since the first study reported by Jones and Smith (1975) noted the complete absence of the corpus callosum in an infant with FAS, there have been numerous studies that have found abnormalities in the corpus callosum of individuals affected by FASDs (Archibald et al., 2001; Johnson, Swayze, Sato & Andreasen, 1996; Mattson, Jernigan, & Riley, 1994; Riley et al., 1995; Sowell et al., 2001). These abnormalities range from complete or partial agenesis to small reductions in the size of the corpus callosum (Sowell et al., 2001). This study also found that the corpus callosum was displaced within the brains of both those with a diagnosis of FAS and also those with prenatal alcohol exposure who lacked a diagnosis of FAS (Sowell et al., 2001). These results suggest that brain defects exist in the absence of the facial abnormalities which are required for the diagnosis of FAS (Sowell et al., 2001).

The basal ganglia are involved in both movement and cognition (Mattson, Jernigan, & Riley, 1994). Many studies have consistently reported reductions in the volume of the basal ganglia in those individuals prenatally exposed to alcohol (Archibald et al., 2001; Mattson et al., 1992; Mattson, Jernigan, & Riley, 1994). Even when overall brain size was controlled for, the volume of the basal ganglia was still reduced in children with a FASD compared to controls (Mattson, Jernigan, & Riley, 1994). Mattson, Jernigan and Riley (1994) also discovered that there was little difference in the size of the overall brain and the basal ganglia between the two children with a diagnosis of FAS and the two prenatally exposed to alcohol without a diagnosis of FAS.

2.4.2 Behavioural and neuropsychological changes. Children affected by FASDs are often labeled defiant and irresponsible due to the undesirable behaviours they often display. People must be aware of these misinterpretations and recognize these behaviours not as the result of poorly raised and defiant children, but as a result of the neurological damage caused by prenatal alcohol exposure (Saskatchewan Learning, 2004). The neurological damage that is sustained in individuals with FASDs may result in behaviours that can be frustrating for both the

child and for those who support him or her (Saskatchewan Learning, 2004). However it is important to remember:

> Children with FAS have permanent, irreversible brain damage – you do not outgrow it, and you cannot fix it, love it away, punish it away or ignore it away. You can, however, provide the types of long-term intervention, support, structure and supervision that encourage, promote and allow adequate function (Luke in Opening Remarks at Children's Commission of BC "Call for Action", 2000 as cited in Saskatchewan Learning, 2004, p. 3.11).

Children diagnosed with partial FAS and ARND also face significant challenges throughout their lives. It is once again important to stress that these disorders may be equally as disabling as FAS (Saskatchewan Learning, 2004). In fact, research has shown that those with partial FAS and ARND may face greater difficulties because they do not display the same facial abnormalities as individuals with FAS (Saskatchewan Learning, 2004). Thus, these individuals may go undiagnosed and are often labeled as problem children because of the undesirable behaviours they display (Saskatchewan Learning, 2004). The behavioural manifestations of impulsivity, poor problem solving, poor judgment, inattention, and immaturity are based on the neurological damage caused by prenatal alcohol exposure (Mela, 2006). This neurological damage results in cognitive impairments, which are then manifested in problems with learning, memory, language, communication, executive functioning, adaptive behaviour, and social skill deficits (Riley & McGee, 2005; Saskatchewan Learning, 2004).

2.4.2.1 Behavioural issues. Behavioural issues arise when the individual is unable to control their activity level and/or emotional reaction in response to internal or external factors (Alberta Learning, 2004). The behavioural disorder most commonly linked with FASDs is attention deficit hyperactivity disorder (ADHD; Riley & McGee, 2005). Streissguth and Giunta (1988) established that 85% of preschoolers diagnosed with FAS also displayed hyperactivity. Children with FAS have also been found to have more eating and sleeping difficulties, display rocking motions, temper tantrums, phobias, enuresis and encopresis than controls matched for age, sex, socioeconomic status, and living situation (Steinhausen, Nestler, & Spohr, 1982). Studies based on parental reports have discussed unmanageable and manipulative behaviours that interfere with productive participation in the home, school, and the community (Mattson & Riley, 2000; Morrissette, 2001). Other studies have also noted an increased risk for psychiatric

disorders, trouble with the law, alcohol and drug use, inappropriate sexual behaviours, and other maladaptive behaviours in individuals prenatally exposed to alcohol (Schonfeld, Mattson, & Riley, 2005; Streissguth et al., 2004).

2.4.2.2 Overall intellectual performance. The intelligence quotient (IQ) of individuals prenatally exposed to alcohol is reported in numerous studies (Mattson et al., 1992; Mattson, Riley, Gramling, Delis, & Jones, 1997; Olson, Feldman, Streissguth et al., 1994; Streissguth, Sampson, & Bookstein, 1998; Streissguth, Randels, & Smith, 1991). Individuals with a FASD often show a wide variation in IQ scores, from a full scale IQ score of 20 (Streissguth, Sampson, & Bookstein, 1998) to a score of 120 (Olson et al., 1998). This large variance in IQ scores means that individuals can range from severely intellectually disabled to normal intelligence (Abkarian, 1992). However, studies have shown that IQ scores for the majority of infants, children, and adults with FAS are between 40 and 80, with a mean of 60 to 65; although findings vary depending on the study sample chosen and the tests used (Niccols, 2007). Another study also reported IQ scores that ranged from 40 to 112 in both the FAS and the alcohol exposed groups (Mattson et al., 1997). In comparison, the IQ scores for just the alcohol exposed group ranged from 64 to 112 and had a mean of 85.6 (Mattson et al., 1997). This is more than two standard deviations below the average for the control group subjects who were matched to the alcohol exposed subjects by age and sex (Mattson et al., 1997). Therefore, this study indicates that significant cognitive deficits are found in those prenatally exposed to alcohol that lack both the characteristic pattern of facial abnormalities and growth deficiency required for a diagnosis of FAS (Mattson et al., 1997). In another study, intelligence, academic performance, and school functioning was evaluated in 265 low socioeconomic status adolescents (Howell, Lynch, Platzman, Smith, & Coles, 2006). One hundred and twenty eight were prenatally exposed to alcohol, 53 were controls, and 84 were special education students (Howell et al., 2006). The results indicated that the adolescents who were prenatally exposed to alcohol had significantly lower Intelligence Quotient (IQ) scores than those in the other two groups (Howell et al., 2006). Howell et al. (2006) also found that youth formally diagnosed with a FASD had significant deficits on the mathematics subtests on the Wechsler Individual Achievement Test (WIAT).

2.4.2.3 Learning and memory. It has been reported that individuals with FASDs have difficulty with both verbal and nonverbal learning and memory (Riley & McGee, 2005). For example, Mattson, Riley, Delis, Stern, and Jones (1996) found that when compared with control

subjects, the children with FAS learned fewer words on the five immediate recall trials and also had difficulty recalling them on the delayed recall trials. They were also less accurate in recognizing the target words from the distracter words on recognition testing, which increased their false-positive errors (Mattson et al., 1996). On the whole, this study suggests that children with FAS have significant learning and memory deficits (Mattson et al., 1996). A more recent study also revealed that adults who were prenatally exposed to alcohol as a fetus, displayed persistent memory impairments and these problems arose from less efficient encoding of both verbal and nonverbal information (Coles, Lynch, Kable, Johnson, & Goldstein, 2010). Therefore, this study discovered that memory impairments persist into adulthood and that individuals without a diagnosis of FAS also experience significant memory impairments throughout life.

Another difficulty that is often seen in individuals prenatally exposed to alcohol is trouble with learning. As students advance in grade level the curriculum becomes less focused on skill development and becomes increasingly focused on applying previously learned knowledge to demonstrate one's understanding of new skills, information, and concepts (Alberta Learning, 2004). Individuals, like those prenatally exposed to alcohol, have difficulty remembering information over a long period of time and therefore, can often struggle with learning. These individuals may have difficulty remembering and learning sequences, understanding basic math problems, learning to tell time, have problems answering questions about material they have read, and experience difficulty writing coherent stories (Alberta Learning, 2004). Therefore, the memory impairments caused by exposure to alcohol in the womb, hinder their ability to learn later in life.

2.4.2.4 Language and communication. Since children with FASDs are often sociable, friendly, and appear younger than their chronological age, their communication difficulties are sometimes overlooked (Abkarian, 1992; Riley & McGee, 2005). However, when compared with controls matched for age, children with FASDs have clear language deficits (Riley & McGee, 2005). Camey and Chemak (1991) studied 10 children with FAS and a control group of 17 children using the Test of Language Development (TOLD). The younger FAS group ranged in age from 4:0 to 8:11 years and the older FAS group consisted of individuals who were 9:0 to 12:11 years old (Camey & Chemak, 1991). The younger FAS group scored significantly poorer than controls on all TOLD measures except the word-articulation subtest (Camey & Chemak,

1991). The older FAS group scored more poorly on three of the five TOLD subtests which included: sentence combining, word ordering, and grammatic completion (Camey & Chemak, 1991). Therefore, as measured by the TOLD, children with FAS have language development problems that can interfere with their ability to communicate effectively.

The facial abnormalities associated with FAS and partial FAS diagnoses, which sometimes include a cleft palate, can also make individuals with prenatal alcohol exposure prone to experiencing speech and language difficulties (Church & Kaltenbach, 1997). The developmental delay in auditory maturation can also make these individuals vulnerable to hearing difficulties (Church & Kaltenbach, 1997). Individuals with a diagnosis of FAS often experience hearing disorders that include: sensorineural hearing loss, conductive hearing loss due to fluid in the ears, and central hearing loss (Church & Kaltenbach, 1997). These hearing difficulties therefore affect the individual's ability to speak properly which can then develop into speech and language difficulties. These language and communication difficulties often have a negative impact on learning and can be recognized when an individual has difficulty expressing his or her feelings and thoughts through language, writing a story or a simple report, making his or her needs known, and exchanging information in a conversation (Alberta Learning, 2004).

2.4.2.6 Executive functioning. Damage to executive functioning occurs during prenatal exposure to alcohol and results in a deficit that is seen in individuals with FASDs (Rasmussen & Bisanz, 2009). Executive functioning involves higher order thinking and action under conscious control (Zelazo & Muller, 2002). It refers to processes such as planning, inhibition, working memory, organized search, flexible thinking, and fluency (Rasmussen & Bisanz, 2009). Executive functioning abilities are thought to be controlled by the frontal cortex (Stuss & Knight, 2002) and prenatal alcohol exposure has been shown to negatively effect the development of the frontal cortex (Rasmussen, 2005).

In order to examine the executive functioning of children with FASDs, Mattson, Goodman, Caine, Delis, and Riley (1999) administered four subtests from the Delis-Kaplan Executive Function System (D-KEFS) to 18 children (aged 8-15 years) with heavy prenatal alcohol exposure. Four domains of executive functioning were tested: cognitive flexibility, response inhibition, planning, and concept formation and reasoning (Mattson et al., 1999). In comparison to the control group of typically developing children, the children prenatally exposed to alcohol had more difficulties on all of the executive functioning tests, even when accounting

for deficits in more basic skills (Mattson et al., 1999). Another study found that children and adolescents with FASDs had difficulty with verbal and nonverbal fluency measures on the D-KEFS, revealing impaired verbal and nonverbal fluency when compared to non-exposed controls (Schonfeld, Mattson, Lang, Delis, and Riley, 2001). More recently, Rasmussen and Bisanz (2009) had 29 children with FASDs (8 to 16 years of age) complete 8 tests from the D-KEFS. The results supported previous research revealing that children with FASD have difficulty with executive function tasks (Rasmussen & Bisanz, 2009). However, these results extended previous findings by indicating that these children also have difficulty on other tasks involving executive functioning, especially card sorting and twenty questions (Rasmussen & Bisanz, 2009). More specifically, these children also had difficulty on other tasks involved in executive functioning, which included: cognitive flexibility, inhibition, some measures of verbal fluency, abstract thinking, deductive reasoning, hypothesis testing, problem solving, and concept formation (Rasmussen & Bisanz, 2009). These deficits in executive functioning may be related to the reduction and thinning of the frontal lobes, deficits in spatial memory, and attention difficulties (Riley & McGee, 2005).

2.4.2.7 Adaptive behaviours and social skills. Adaptive behaviours are behaviours related to age-appropriate skills, learning, and the ability to perform community rules, household routines, chores and self-care (Alberta Learning, 2004). Studies suggest that children prenatally exposed to alcohol are at a high risk for developing problem behaviours that can interfere with their participation in home, school, and social environments (Riley & McGee, 2005). Alcohol-exposed children are more likely than non-exposed children to be rated as hyperactive disruptive, impulsive, or delinquent (Mattson & Riley, 2000; Roebuck, Mattson, & Riley, 1999).

Social skills include being able to understand and express the social conventions necessary for effective communication, participation in daily social interactions, and the demonstration of behaviours that allow for the development and maintenance of social relationships (Alberta Learning, 2004). Children prenatally exposed to alcohol have been described as displaying indiscriminant social behaviour and as having difficulty comprehending social cues, and communicating in social arenas (Streissguth & Giunta, 1988; Streissguth & Kanter, 1997). Children with prenatal alcohol exposure have been found to have poorer social skills than non-exposed controls even when compared to peers with similar verbal IQs (Thomas, Kelly, Mattson, & Riley, 1998). Furthermore, social skill deficits seen in children with a

diagnosis of FAS did not differ significantly from the deficits seen in those without the full syndrome diagnosis; this suggests that impaired social behaviour is not limited to those children with the most severe prenatal exposure to alcohol (Schonfeld, Paley, Frankel & O'Connor, 2006).

The above discussion reveals the significant damage that prenatal alcohol has on the developing brain and the subsequent behavioural and learning difficulties that commonly follow. However, not all research has focused on the negative outcomes that prenatal alcohol has on the affected individuals. In fact, several studies have focused on protective factors, successful school experiences, and resiliency in those with Fetal Alcohol Spectrum Disorders.

2.5 Resiliency and Fetal Alcohol Spectrum Disorder

Prior to discussing research literature that explores aspects of resiliency in those diagnosed with a Fetal Alcohol Spectrum Disorder, a definition and greater exploration of resiliency is warranted. Extensive research has been conducted in the area of childhood resilience (Masten, 2001). Numerous psychologists and psychiatrists have wrote at length about the significant number of children from high-risk situations that have demonstrated a notable capacity for resilience, despite experiencing overwhelming odds (Masten, 2001). According to Luthar, Cicchetti, and Becker (2000) resiliency is the ability to positively adapt despite experiencing significant adversity. Another definition describes resilience as a set of adaptive cognitive, behavioural, and emotional responses to acute or chronic adversities which can be unusual or common. These adaptive responses can be learned and are within the grasp of everyone; resilience is not a rare quality only given to select individuals. While many factors affect the development of resilience, the most important one is the attitude you adopt to deal with adversity. Therefore attitude is the heart of resilience (Neenan, 2009).

Resiliency research is largely focused on understanding the processes that allows for this ability to positively adapt, in spite of serious threats to development (Masten, 2001). Masten (2001) argues that resilience is an inferential and contextual construct that requires two main judgments. First, individuals are not considered resilient if they have never experienced a significant threat to interfere with normative development. I would argue that being born with the type of brain damage described in the preceding paragraphs would be considered a significant threat that interferes with normative development. Therefore, individuals with FASDs who are able to positively adapt, and in some cases experience success, would be

considered resilient according to this first judgment. The second judgment Masten (2001) discussed involves assessing or evaluating the quality of adaptation or development as "good' or developmentally on track. Although individuals with FASDs often experience set backs in normative development, due to both internal and external factors, if they are able to adapt to their situations and get themselves back on track, they would fulfill Masten's second judgment when understanding resiliency. Given that a better understanding of resiliency has been presented, the following paragraphs discuss research related to protective factors, success, and resiliency in individuals with Fetal Alcohol Spectrum Disorders.

In a cross-sectional natural history study, Streissguth, Bookstein, Barr, Sampson, O'Malley, and Young (2004) provided data to support the notion that stable families with long lasting parent-child relationships are a critical protective factor in helping children with FASDs avoid harmful outcomes in life. These harmful outcomes included: major disruptions in schooling, trouble with the law, inappropriate sexual behaviours, extensive confinements, and alcohol and drug problems (Streissguth et al., 2004). Another critical protective factor for those with FASDs is an early diagnosis (Streissguth et al., 2004). Therefore, Streissguth and colleagues (2004) believe that physicians can serve a crucial role in improving the outcomes for individuals born with FASDs through: performing systematic questioning about maternal alcohol consumption, making the diagnosis themselves and/or by suggesting appropriate referrals, and encouraging parents to advocate for their children at school and in their communities. The risk of negative outcomes in life for those with FASDs may be reduced through the coming together of families, communities, and physicians to ensure that children with FASDs are not only diagnosed as early as possible, but are also raised in stable and nurturing homes that recognize and accommodate for their individual needs (Streissguth et al., 2004). A study by Olson, Oti, Gelo, and Beck (2009) also focused on the importance of good quality care giving and a stable home environment in achieving successful outcomes for those with FASDs. Clinical observations in this study revealed that caregivers and families are the primary advocate for individuals with FASDs throughout their lifetime (Olson, Oti, Gelo, & Beck, 2009). Two studies that focused on the school experiences of those with FASDs also found that parental support and advocacy contributed to persistence in high school and experiencing success in school (Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006;). Therefore, in order to increase the likelihood of individuals prenatally exposed to alcohol experiencing resiliency despite

significant adversity, it is vital that high quality care giving and a supportive and stable home environment are emphasized in all interventions.

2.6 Summary

The belief that heredity was the root of all intellectual disabilities dominated the thinking of the general public until the late 20th century. Fortunately, today it is generally accepted that prenatal alcohol exposure is one of the leading known causes of preventable birth defects and developmental disabilities in the western world (Ryan, Bonnett, & Gass, 2006). Diagnostic guidelines have also improved overtime. Since Jones and Smith (1973) first outlined the diagnostic criteria for FAS, guidelines have continued to become increasingly clearer and more specific. Over the years, numerous studies have also been conducted to further explain the extensive physical, intellectual, and behavioural damage that occurs as a result of prenatal alcohol exposure. These studies have found alterations in the brain, specifically the corpus callosum and the basal ganglia, of those prenatally exposed to alcohol. These permanent alterations of the brain commonly lead to changes in behaviour and cognitive functioning throughout the lifespan (Riley & McGee, 2005). For example, decreased intellectual and memory performance, difficulty with language and communication, executive functioning problems, and adaptive behaviour and social skill difficulties exist as a result of the maternal consumption of alcohol during pregnancy. Although significant damage occurs when a mother prenatally exposes her unborn child to alcohol, there are interventions that can be used to improve the outcomes of the affected individuals. Several studies have focused on the protective aspects that high quality care giving and a supportive and stable home environment can have on those with FASDs (Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006; Olson, Oti, Gelo, & Beck, 2009 Streissguth et al., 2004). Thus, individuals prenatally exposed to alcohol are more likely to overcome adverse situations and experience success and resiliency when knowledgeable caregivers provide advocacy, support, and stability.

Research related to the diagnostic criteria and the effects that prenatal alcohol exposure has on the brain, behaviour, and cognition has increased over the past thirty-seven years since the term fetal alcohol syndrome was first coined. However, very little research has explored FASDs through the eyes of those who are actually diagnosed with these disorders. Increased information is needed to better understand how individuals with FASDs believe prenatal alcohol exposure has affected their lives in relation to their social experiences in and outside of the

school environment. In order to expand educators' understanding and ability to address students' needs, effective interventions need to be based on the educational and individual needs of these individuals. Therefore, the aim of this study was to further contribute to this small body of research by seeking the point of view of those who have been diagnosed with a FASD. By sharing their experiences of being diagnosed with a FASD in school and the community, these individuals contributed valuable knowledge to this area. This study provides a greater understanding of the school and life experiences of individuals prenatally exposed to alcohol and also how they were able to increase their resilience by overcoming significant adversity.

CHAPTER 3: METHODOLOGY

3.1 Rationale for Qualitative Methodology

Qualitative research attempts to answer questions about what an experience is like for a particular individual or group of people (Merriam, 2002). It is a way to understand and explore the meaning individuals or groups give to a social or human issue (Creswell, 2009). Qualitative inquiry can be useful for exploring phenomenon about which little is known (Strauss & Corbin, 1990). The main goal of qualitative research is to gain a greater understanding of a phenomenon, how it is experienced by the participants, and the meaning and significance it holds for them (Merriam, 2002). Merriam (2002) stated, "all qualitative research is characterized by the search for meaning and understanding, the researcher as the primary instrument of data collection and analysis, an inductive investigative strategy, and a richly descriptive end product" (p. 6).

Merriam (2002) noted several characteristics to describe qualitative research. First, qualitative researchers emphasize that individuals socially construct the meaning of their world. In contrast to a quantitative research paradigm which holds the belief that reality is a fixed, single, or measurable phenomenon; qualitative researchers view reality as multiple constructions and interpretations that are in a state of constant flux and change throughout time. Qualitative researchers are interested in understanding specific phenomenon at a particular point in time and in a particular context. Second, in qualitative research, the researcher is the primary agent for data collection and data analysis. The researcher interprets the data, clarifies and summarizes material, checks with participants for accuracy of interpretation, and explores unusual or unexpected responses. Third, qualitative research is an inductive process, as researchers use data to generate concepts, hypotheses, or theories rather than deductively developing hypotheses to be tested. Finally, the end product of a qualitative inquiry is richly descriptive, as data generated from words, quotations, field notes, documents, or participant interviews are used to convey what the researcher has learned about a particular phenomenon.

Much of the existing research concerning Fetal Alcohol Spectrum Disorders has been quantitative in nature. More information is needed to better understand how individuals with FASDs believe prenatal alcohol exposure has played a role in shaping their school and life experiences, specifically their social interactions and peer relationships. Thus, it was the aim of the present study to help better understand this understudied area. Two research questions guided this inquiry. First, what are the school and life experiences of those diagnosed with Fetal

Alcohol Spectrum Disorders? Second, what has allowed these individuals to achieve success in school and life situations? Through utilizing a basic qualitative approach (Merriam, 2002), I developed an in-depth understanding of the participants' school and life experiences, while also exploring themes of resiliency and success.

3.2 Basic Qualitative Research

Merriam's (2002) basic qualitative approach was utilized to explore the school and life experiences of individuals diagnosed with FASDs and how this diagnosis has shaped their social interactions and relationships. Merriam (2002) argued that qualitative researchers conducting a basic qualitative study are interested in "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences" (p. 23). The main purpose is to gain a better understanding of how people make sense of their lives and experiences (Merriam, 2002). Data is collected through interviews, observations, or document analysis, and is analyzed by recognizing recurrent patterns within the data (Merriam, 2002). The findings are the recurring patterns or themes derived from the data by the researcher (Merriam, 2002). Therefore, the end product is the researcher's interpretation of the participant's understanding of the phenomenon being studied (Merriam, 2002). Although all qualitative research is interested in how people understand their lives and worlds, a basic qualitative inquiry's most important goal is to uncover and interpret these meanings. Since the main purpose of the current research was to further understand the educational and life experiences of individuals with FASDs, a basic qualitative approach was best suited to achieve this understanding. Although phenomenology could have been used to explore the lives and educational experiences of individuals diagnosed with a FASD, this method asks participants to explore many abstract concepts that could possibly be too difficult for many individuals with FASDs to fully comprehend. Therefore, a basic qualitative approach was the method chosen to explore this topic.

3.3 Participant Selection and Recruitment

Upon University of Saskatchewan Ethics Board Approval, (See Appendix A) purposeful sampling was used to recruit four adults diagnosed with a FASD to participate in the current study. The goal of purposeful sampling "is to select cases that are likely to be 'information-rich' with respect to the purposes of the study" (Gall, Gall, & Borg, 2007, p. 178). This means that the participants selected were knowledgeable about the phenomenon under study and were

willing to participate fully (Morse & Richards, 2002). Criteria used to determine participant eligibility included: (1) Age: All participants were between 18-30 years of age; (2) Diagnosis: All participants were diagnosed with FAS, FAE, partial FAS or ARND (as reported by the individual); (3) Ability and willingness: All participants were willing and able to share their school and life experiences of being diagnosed with a FASD; (4) Well-being: All participants were not in any immediate crisis (e.g., currently experiencing emotional, physical or psychological distress); and finally (5) History: All participants currently were, or previously have been, a student in school.

Participants were recruited through a *Call to Participate* notice (See Appendix B). The notice was posted at the FASD Support Network of Saskatchewan, Community Living Association of Saskatoon Incorporated, Central Urban Métis Federation Incorporated (CUMFI), and the Saskatchewan Prevention Institute, all of which are located in the city of Saskatoon, Saskatchewan, Canada. The notice was also posted on the FASD Support Network of Saskatchewan website. These associations support families and individuals who are diagnosed with FASDs. After a few weeks with no response from potential participants the researcher contacted the above organizations and set up formal meetings with the directors to discuss the research and possible participant recruitment. Directors at both the FASD Support Network of Saskatchewan and CUMFI then contacted potential participants who met eligibility criteria to see if they were interested in the study. Before the interview process began, each participant was screened for eligibility through a telephone conversation with the researcher (See Appendix D). The researcher assessed whether or not the individual spoke well and clearly enough to understand the questions. This was an important process to ensure participants understood what was being asked of them and to protect their interests. Out of the five potential participants who contacted the researcher, none were rejected based on difficulty communicating. However, one potential participant was not included in the study because a suitable meeting time and place could not be organized for the interview due to conflicting schedules. After the screening process, if participants agreed to take part in the study, a mutually agreed upon time and place for the first interview was established.

3.4 Data Generation

Some difficulty was experienced in establishing interview times and researcher flexibility was an asset during this process. After the issues with time were sorted out, each individual met

with the researcher for one main interview. All participants were given the opportunity to review the transcript. However, only two sat down with the researcher and made significant changes to the document, while another participant chose to review the transcript through e-mail. Interviews were conducted in a public but private location that was convenient for both the participants and the student researcher (e.g., A board room at CUMFI - Central Urban Métis Federation Incorporated). Informed consent was obtained through a written consent form which was introduced at the beginning of the first interview (See Appendix C). The consent form clearly outlined the details of the research project and the participant's rights and obligations, including their right to withdraw from the study at any time without penalty. Signing the form signified the participants' understanding of these rights and obligations, and was accepted as consent to participate. The researcher reviewed the content of the consent form orally with each participant and they were given a copy of the consent form at the interview.

Any information that could potentially identify participants was altered or deleted, and each participant has been given a pseudonym. The initial interviews were digitally recorded and preceded for approximately 45 to 150 minutes. In order for the participants to feel as comfortable as possible, I began each interview by sharing my personal story about who I was and what made me interested in studying this topic. This often led the participants to ask questions about my sister and her children. Once participant even informed me that he was now more comfortable sharing his story with me because he knew I would not think he was slow or stupid. After each interview, the researcher then transcribed the information. Each interview consisted of open-ended questions, such as "What made you want to take part in this study?", "Describe what elementary school was like for you?", "How did you find making friends in school?", "What are some things that have helped you be successful in school?" and "What has your experience of being diagnosed with (FAS, partial FAS, or ARND) in school been like?". Following the interview, participants were verbally debriefed and thanked for their participation. Participants were then informed that they would be contacted for a follow-up interview within one month's time.

At the follow-up interview, participants were provided with a copy of their transcript from the interview which the researcher and participant discussed to aid in member checking. Participants then signed the transcript release form. After the participants reviewed the transcript with the researcher, follow-up questions were asked to provide any needed clarification from the

first interview. Two participants declined to make a second meeting with the researcher and of these participants, one decided to review the transcript electronically. Therefore, in order to obtain consent to use the data in the transcripts, the researcher contacted the director at CUMFI and was able to meet with the participants to sign the transcript release form.

3.5 Data Analysis

Data analysis is the process through which the researcher makes sense out of the data (Merriam, 2002). This process involves "consolidating, reducing, and interpreting what people have said and what the researcher has seen and read" (Merriam, 2002, p. 176). Data analysis begins by identifying segments within the data that answer the research question (Merriam, 2002). Upon reading the transcript for the first time, the researcher made notes, comments, and observations in the margins of the transcript; Merriam (2002) refers to this process as open coding. After going through the entire transcript in this manner the notes, comments, and observations became the codes that were then transferred onto cue cards. The cue cards were reviewed and those that fit together were put in the same group. Once each card had a group, the cards were examined for a common theme. The themes were then derived from these groupings and the theme names formed. This analysis extends beyond what any individual may see in his or her own experience (Janssen, Henderson & Vedam, 2006). This is because the individual has a deep understanding of his or her own experience, while the researcher has access to the insights of many participants (Janssen, Henderson & Vedam, 2006). The researcher focused on the unique experiences of each participant and the commonalities and differences among them. This in turn led to a greater understanding of the school and life experiences of individuals with FASDs. The present study also incorporated resiliency theory (Luthar, Cicchetti, & Becker, 2000) as a framework for understanding and analyzing the data.

3.6 Evaluation Criteria

Qualitative research examines a study's authenticity, trustworthiness, and rigor based on its alignment with the philosophical assumptions underlying the paradigm (Merriam, 2002). This pertains to the study's cohesiveness. The present study was based in a relativist ontology, which argues that "realities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form on the persons who hold them" (Guba, 1990, p. 27). A constructivist perspective of reality also informs the current study, which Schwandt (2001) defines as,

> the belief that the mind is active in the construction of knowledge… constructivism means that human beings do not find or discover knowledge so much as construct or make it…We do not construct out interpretations in isolation but against a backdrop of shared understandings, practices, language, and so forth. (p. 31)

And finally, a subjectivist epistemology was used to understand the data generated in the present study. A subjectivist epistemology outlines that the "inquirer and inquired into are infused into a single (monistic) entity. Findings are literally the creation of the interaction between the two" (Guba, 1990, p. 27). The reason these ontological, epistemological, and theoretical positions were chosen is because the researchers own belief systems best align with these paradigms. Therefore, if the current study upholds the beliefs within these paradigms it will have authenticity, trustworthiness, and rigor.

In order to further establish the trustworthiness of the present basic interpretive study, the researcher incorporated both traditional and relational aspects of evaluation criteria. The traditional evaluation criteria examined includes credibility and auditability (Lincoln & Guba, 1985); while discussions of positionality/standpoint judgments and voice were examined in order to meet relational evaluation criteria (Lincoln, 1995).

3.6.1 Credibility. Sandelowski (1986) argued that "a qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own" (p. 30). Sandelowski (1986) also stated that credibility is increased when the researcher describes and interprets his or her own behaviour and experiences of being a researcher in connection to the behaviour and experiences of the participants. The goal was to create rich and thick descriptions about the lives of individuals diagnosed with FASDs and provide enough information so that readers in a similar situation are able to relate to the stories of the participants in the study.

Additional strategies were employed in order to increase the present study's credibility. For example, participants were provided with the opportunity to review a copy of the transcript from their interview. The researcher offered to examine the content with the participant and answered any questions that arose. This concept of using member checks aligns with a subjectivist epistemology because the participants are provided with the opportunity to correct any errors and to recall or add facts or feelings that were not mentioned in the first interview. A

pilot test was also conducted with the researchers nephew in order to determine whether or not the interview questions were leading and to be sure that they are concrete and understandable.

3.6.2 Positionality/standpoint judgments. Positionality or standpoint judgments involve the qualitative researcher expressing his or her own stance and position in regards to the research topic (Lincoln, 1995; 1998). This has also been called the theoretical position of the researcher, where the researcher's motives, presuppositions, and personal history consequently shape the research they undertake (Caelli et al., 2003). Caelli et al. (2003) argued a researcher's motives for examining a certain research topic is never a random decision and an explanation of the researcher's theoretical position is particularly important in establishing credibility. As a researcher, I chose to discover more about individuals diagnosed with FASDs because this is a topic to which I have a deep personal connection. I grew up with a sister who was prenatally exposed to alcohol and have experienced firsthand the overwhelming effects this disorder can have on the lives of all those involved. I also have a nephew who has been diagnosed with partial FAS and a niece with ARND. Over the years I have watched them struggle daily with numerous behavioural issues, speech and language difficulties, and grave social impairments. Thus, it is my personal aim to gain a deeper understanding of this disorder so that I am able to help educate and improve the lives of those affected by FASDs. Due to this close personal connection I was aware that I had to monitor and illuminate my own biases and feelings when conducting this research.

3.6.3 Voice. Lincoln (1995) argued that qualitative researchers have a responsibility to seek out those voices that are silenced within society and make their stories heard. Despite the profusion of research regarding FASDs, the voices of individuals prenatally exposed to alcohol are not commonly found in the literature. Thus, the present study aimed to allow the voices of these individuals to be heard.

3.7 Ethical considerations

Participation in the current study was voluntary and the participants had the right to withdraw from the study at any time. Informed consent was established with each participant before proceeding with the interview. The digital recordings of the interview were available only to the researcher. Data from this study will be properly stored for the required five years in the office of my supervisor Dr. Laureen McIntyre, in the Department of Educational Psychology and Special Education in agreement with the University of Saskatchewan regulations. No

identifying information was used within the present study; instead each participant was given a pseudonym.

The current study encountered unique ethical considerations in obtaining approval from the University of Saskatchewan Ethics Board that are worth noting. Due to the vulnerable nature of the participants I was working with, the study was considered above minimal risk. The Ethics Board was mainly concerned that the adults selected to participate in the study knew what they were being asked so they could give informed consent. Therefore, the main challenge I faced as a researcher was lowering the level of readability of the consent form so that it could be easily understood by potential participants. Another ethical consideration I faced as researcher was outlining how I would determine participant eligibility. The research committee wanted to be sure that I would get enough information from the interviews with my participants so therefore I developed the telephone script which was used to determine participant eligibility (See Appendix D). Despite these challenges the study progressed and was finished within a timely manner.

In the subsequent chapter, the demographics of the participants are discussed and the themes presented.

CHAPTER 4: RESULTS

In this chapter, I introduce the participants who contributed to this research. In order to protect participant confidentiality, pseudonyms were chosen. Participants' quotations were often edited to protect confidentiality and increase readability. For example, specific names were altered or eliminated and repetitive and unnecessary words (e.g., yeah, you know, like) were deleted. The research question was then discussed and the information found was revealed. Next, the three major themes were identified in the stories of the participants and meaningful quotes were discussed and linked together. For organizational purposes the themes are ordered numerically. The themes found were as follows: (1) "I don't fit in": negative school experiences lead to anger and frustration toward diagnosis; (2) intergenerational alcoholism, child abuse, and drug addiction; and (3) healing the wounds: sources of strength, success and helping others. Numbering does not indicate rank or order of importance. Finally, the themes were reviewed and the major findings discussed once again to end in a summation of the chapter.

4.1 Participants

The participants in this study included four adults from Canada; two of whom were Aboriginal, and the others Caucasian. Participants ranged in age from 19 to 30 and included two males and two females: Derek, Madison, Teresa, and Brandon. A brief synopsis of each participant is presented here in order to provide a better understanding of who these participants are, what they have been through, and where they are today. Further rich and complex details of their lives will emerge as the rest of the chapter unfolds.

The first participant to be interviewed was Derek. At the time of the interview he had recently celebrated his 30th birthday. In his youth, Derek was diagnosed with FAE as well as ADHD. Based on Derek's descriptions of his upbringing, he was raised in a low socioeconomic environment. He experienced many struggles throughout his life, especially in school, that were related to his diagnoses (e.g., hyperactivity, distractibility, and communication issues). However, many of the struggles that Derek faced in life also had to do with his home environment. He grew up in a physically and emotionally abusive home where alcohol was being abused by both of his parents. During his teenage years he also began abusing drugs and alcohol himself. Despite these hardships, Derek graduated high school, went on to become a hockey coach, and was 154 days sober at the time of the interview.

The next participant to be interviewed was Madison, who was 20 years old at the time. Madison was diagnosed with partial FAS when she was a young child. She also grew up in a low socioeconomic environment where her mother abused alcohol. In fact, when Madison was around ten years of age, she and her siblings were put into foster care because her mother was not able to properly care for them. However, once she began living a sober life, Madison's mother regained custody of her children and raised them until they were grown. Madison credits her mother for providing her with the strength and courage to speak out and stand up for herself when she needed assistance or did not understand something being taught in class. Madison graduated high school and has plans to attend the social work program at the University of Saskatchewan in the near future.

Teresa was the third interview completed by the researcher. At the time of the interview Teresa was 30 years old. She revealed that although she was diagnosed with FAE when she was a child, she did not find out about her diagnosis until she was an adult while looking through her social work file. She was adopted as a young child into an abusive home in a low socioeconomic environment. Teresa suffered both physical and emotional abuse at the hand of her adoptive mother. During her school years, she always felt like she did not fit in and had a hard time making friends. Drama class proved to be the place where Teresa felt most comfortable. Here she was able channel the pain she was feeling inside into her drama performances, which helped her cope with some of her emotions. Later in life Teresa became addicted to drugs and alcohol. At her lowest point she was injecting herself with drugs and engaging in prostitution. One day Teresa realized that she was meant to do more with her life and began the process of getting clean and sober. Today Teresa has maintained her sobriety and even uses her story to inspire and help other addicts who are in the same place she was years ago. Recently Teresa was accepted into a post secondary institution where she will be taking the community addictions program.

The last and final participant to be interviewed was Brandon. Brandon was finishing up his final year of high school at the time of the interview and was 19 years of age. Brandon was adopted into a middle class home around the age of one. He grew up with two siblings and very supportive parents. Brandon had numerous difficulties with school and was on a Personal Program Plan for most of his high school years. He also experienced difficulty making friends and often got into trouble at school due to his disruptive behaviour. However, once he began

playing sports he made many new friends and began enjoying school. Brandon has recently graduated grade 12 and is working at a local community center.

Criteria used to determine participant eligibility included: (1) all participants were between 18 to 30 years of age, (2) all participants were diagnosed with FAS, FAE, partial FAS or ARND, (3) all participants were willing and able to share their school and life experiences of being diagnosed with a FASD, (4) all participants were not in any immediate crisis (e.g., going through emotional, physical or psychological distress), and finally, (5) all participants currently were, or previously had been, a student in school. Participants were recruited through their contact with community organizations designed to provided services for individuals affected by FASDs and their families. Thus, the participants in the current study have accessed these service to improve their quality of life. Given this factor, these participants demonstrated aspects of resiliency. Next, the three major themes are presented and discussed in the paragraphs that ensue.

4.2 Theme 1: "I Don't Fit In": Negative School Experiences Lead to Anger and Frustration Towards Diagnosis

"At times I was bullied in school and I didn't really have a lot of friends. No one really wanted to be friends with anyone who was slow."

Derek, Madison, Teresa, and Brandon all experienced difficulty making friends, were bullied by their peers, and got into trouble at school. Although each participant had slightly different experiences, common to all four individuals was a sense that they did not quite fit in. For example, Derek explained:

> Growing up I had to avoid a lot of fights because I was bullied at school. And I didn't really have a lot of friends when I was a kid cause I was sort of a loner…I was also a follower, I always listened to what others told me to do. People would tell me to do something and I would do it because I wanted to have friends.

And Madison revealed:

> Being out in the hallway was not good for me. I felt like an outcast. Being bullied in school was also hard for me and it made my days at school worse. Some days I didn't even want to go to school 'cause I was worrying about what they would say next.

Teresa described her experiences in school:

> It [elementary school] was hard, I didn't fit in. I had a lot of stuff going on in my home so I acted out in school. In grade 4 I was the class clown. I would throw my apple at the

> chalkboard, take my sandwiches apart and throw them on the ceiling. Just very bizarre stuff…I really acted out a lot 'cause there was a lot of abuse going on at home and stuff so…I don't know, I never felt like I really fit in. I was always on the outside looking in. The only way I did get attention was by being bad or out of control. Well not so much out of control but just kind of wild, trying to be funny, trying to be different. Because I always felt like I didn't fit in and then I was like okay then, I'm going to be different.

Finally, Brandon told his own experiences of making friends in school:

> Sometimes it's hard. It's not easy making friends cause some people when they come to school they are mean to me. This makes it hard. I am shy sometimes too so that is hard. I never really had any friends until I got into high school 'cause I started to play sports.

As previously stated above, common to all stories is a sense that they did not belong and were outsiders at school. Another commonality that Derek, Madison, and Brandon discussed was getting into trouble at school. For example, Derek recalled his experience with teachers at his school:

> Well I was the class clown so they [the teachers] didn't like me much. I was hyperactive like I said before so I was sent outside to the hallway all the time.

Madison explained:

> I didn't like my one teacher because we would disagree a lot about different things. He would try teaching one thing and I would disagree and we would get into arguments. I had my opinions and I wouldn't agree with him and then I would get upset and get in trouble. It would get so personal and that's what would get me into trouble.

Brandon described his experience:

> Well the teachers are all right I guess…it's just hard when I get into trouble and they send me to the office. I don't like that.

Another common experience that Teresa, Madison, Derek and Brandon all discussed was difficulty with school subjects, especially mathematics. Here Teresa explained how frustrating math class could be:

> Being in math class, grade 10 math class, the teacher would do the question on the board and I got it and it would make sense. Then I would sit down in my desk and try to do my work and I couldn't do it! I didn't get it. She would come over to my desk and do the question step by step with me and it made sense. She would get up and leave. Then the next question I would try to do on my own and I couldn't! I remember one day ripping up my questions and being so pissed off cause I didn't get it. And I remember students in the class being annoyed or fed up because I was always putting up my hand because I didn't

> get it and I wanted to understand it but I just didn't get it. And other people didn't care or whatever but I wasn't like that. I wanted to get it and I wanted to learn.

Madison discussed her difficulty with school:

> I didn't pay attention because I didn't get it so that's what made me not want to listen. Math was really hard for me. It's still really hard and I still don't like it. Honestly I really don't know how I passed!

Derek revealed his difficulties with communication:

> In elementary school I was going to special needs classes to work on subjects like math or whatever. I also worked on my speech impediment…they would tell me to slow down when I was talking, "It's not a race" they would say. To this day I still find it hard to comprehend what other people say and to communicate with people.

Finally, Brandon revealed his trouble with school:

> I am in modified classes you know. Like I do not take the same tests as everyone else does. I have an E.A. [Educational Assistant] who helps me beside my desk cause I don't get things as easy as everyone else.

Having these negative experiences in school, which were commonly related to their diagnosis, often led the participants to become angry and frustrated with their diagnosis. For example, Brandon discussed how he sometimes feels about having been diagnosed with a FASD:

> It makes me angry sometimes. The way I am and the stuff I do sometimes it gets me angry. I can't do most things that other people can and it makes me angry. It's really hard like in school and stuff.

Derek explained his frustrations:

> You know I didn't ask to be brought into the world this way…having FAS. You know I was born this way you know and I can't do nothing about it but live my life. But I just want other people to know that it is hard for some people to accept, you know that I have a problem. But that's just the way it is, I can't change it.

Teresa discussed the anger that was inside of her:

> One day I was walking towards my best friend and she looks at me and asks "Are you okay" and I am like "Yeah why?" She's like "You look like you're gonna kill someone." And I was like, "I do?" Like I just had this wall up, don't talk to me, don't look at me, because I am such a loser and why would anyone want to talk or look at me? So I put out this f you image, don't look at me, don't talk to me, I don't exist. You know I just had all

> this anger inside of me because I had some self esteem issues and also because I didn't fit in.

In summary, Derek, Madison, Teresa, and Brandon each described the difficulties that they had at school. Being bullied, feeling like they did not fit in, and having difficulty making friends, were all common themes to the participants. Another commonality among all four of the participants was getting into trouble at school. The trouble that the participants got into at school was often because they did not understand what was being taught in the classroom. These difficulties with school often caused the participants to become angry and frustrated with their diagnosis. The following theme relates to family alcoholism, physical abuse, the participants own experience with drug and alcohol addiction.

4.3 Theme 2: Intergenerational Alcoholism, Child Abuse, and Drug Addiction

"Love for me came in a bottle. A gallon of wine. If there was no more alcohol I would get hit. That's how I grew up to be numb."

Derek, Madison, and Teresa all spoke candidly about a family history of alcholism. Alcoholism was not a secret, and from an early age the participants knew what alcohol was and how it affected the people who were abusing it. For example, Derek talked about his experience growing up in a home where his parents drank and were physically abusive:

> I was abused when I was a kid. I was physically hit. When they [his parents] were drinking everything was fine…well not fine, but better. When the money ran out so did the alcohol and that's when I had to watch out.

Teresa discussed her experience being abused by her adoptive mother:

> I hated Friday's, hated them, and I loved Mondays. Which is usually the opposite for most kids, but this is how I escaped my home. So school was my safe haven. School was actually where I got to be myself without getting hurt or punished or ridiculed and even if it was by the teachers it was proper punishment…well not punishment, but discipline. And it was safe at school. Even if I was wild and out of control because I definitely could not do that at home. Cause everything I did at home, which was not wild or out of control, was punished. So I got to go to school and not only be myself, but be totally off the wall, and it's not like it was okay but it's not like I was being completely ridiculed or unfairly punished.

Although Madison did not experience abuse growing up, she spoke about family alcoholism:

> She [her mother] would always tell me about my family and how they all drink and how they are all dying one by one and I did not want to grow up like that. My mom quit

> drinking for us [her children]. I was around ten I think when I got put into a foster home and when I got out she was sober and healthy and she could take care of us. But I was just so used to people always drinking and I just thought that that was the way it was supposed to be. And she was like "NO!" She taught us about family traditions and how to live a healthy life. So I am really happy that I learned these things from her. She always says, "what doesn't kill you makes you stronger" and I like that message.

Teresa talked about the alcoholism and abuse in her family:

> You know my dad is an alcoholic, he's dying from it, and my mom died of alcoholism. I didn't get to know her very well, we got into an argument over my older sister. There was some abuse from my sister to her children and I phoned social services on my sister, which was really hard.

She also talked about the association between alcohol and violence she held from an early age:

> I always grew up with some knowledge in my head that drinking was scary, that drinking was unsafe. When I was adopted all the way up until I was 13 or 14 I had never seen alcohol or been around it. I had a sleep over at a friends house one night when I was around that age and she told me that her parents were out drinking that night and I didn't sleep that night because I was absolutely convinced that they were going to come home that night and beat the crap out of me. Now, where would I ever pick that up if I had never been around alcohol? Something inside, deep inside me knew. Something happened to me when I was a baby and I don't know what it was but I know that it was violent…I just know.

These early experiences with alcoholism within their families and in some cases physical and emotional abuse, shaped how the participants viewed alcohol and other drugs. Derek, Madison, and Teresa all experimented with drinking at an early age. Derek and Teresa also experimented with drugs and unfortunately became rapidly addicted. Here, Derek spoke about his experience with drugs and alcohol:

> You know I've done some stupid things in the past. Drugs played a big role in my up bringing, same with alcohol. You know, like I said drugs played a big part in my life. You know, I don't need it and I don't want it but if I have money, I am going to buy it. So I want to go to treatment and get help. You know its difficult to talk about it but at the same time if its going to help someone else out then I'm all for it.

Madison talked about her experience with drugs and alcohol in high school:

> Having friends who were doing drugs and stuff made things hard 'cause I didn't want to take drugs. I would go out drinking with them but I never touched drugs. Then one day I

> even stopped that because I would see my aunties and I didn't want to be like them. So I quit [drinking] and I lost a lot of friends.

Teresa explained how she started drinking and experimenting with drugs:

> I got into partying between about grade 9 and 10. 'Cause that's what you did on the weekends was go out and get drunk. Well that's was what we did anyways. I did quite a bit of drinking but I got out of that really fast. So in grade 10, I was in the pot head crowd, and you know they would ask me almost everyday at lunch time if I wanted to go and get high. I was dead set against drugs and I would say no every time. But then one day they asked me, and I don't know why, but I said yeah, let's go check it out. So I went and got high but I think it was laced with something because I was so paranoid and I thought I was going to die. So I don't know, there was kind of a lot of partying going on and stuff in grade 9 and 10. I stopped drinking by the time I hit 11th grade because it wasn't like I was having blackouts, but I was very, very promiscuous. You know, I wanted the love, and looking back at it, I was desperate for it. So, if it meant for that little short amount of time that someone liked me enough to want to be with me, then that was good enough.

After Teresa phoned social services on her sister for child abuse, Teresa and her mother did not speak for ten years:

> For 10 years I didn't speak to her! This shattered, literally shattered something so deep inside of me so then I hit the drugs and I hit them hard. I was like the dope head of dope heads and it got bad it got really, really bad and I eventually turned to harder drugs. Like, for a long time it was pot and I was obsessed with it. I lived and breathed it, that's all I wanted. Nothing else mattered. I always had a line that I wouldn't cross, that I would never do cocaine, and one day, for whatever reason, just like the day that I decided to try pot for the first time. There was a line of coke in front of me and I did it. The next day I was smoking crack, and it just got horrible. I was on 20th [street] for a little while, not proud of that. I had people inject me with needles a few times, and I even tried to inject myself a few times. I remember being really dope sick one time, picking up a needle and giving myself a shot of Hep[atitis] C, and I think that was my wake up call, literally. When I got the phone call that I had Hep[atitis] C, it was like God was saying, "Do it again and you are going to die." And it was so crystal clear, like "Okay, Teresa wake up! What the hell are you doing with your life?" I could've gotten AIDS, I could have been killed, I could have been raped, I could of overdosed.. but here I am alive, so I have to do something with it!

To summarize, Derek, Madison, and Teresa all spoke about their experiences with intergenerational alcoholism and how this shaped their views and behaviour with drugs and alcohol. Derek and Teresa also discussed the physical and emotional abuse that they

experienced growing up and how they both turned to drugs and alcohol to numb the pain. The final theme that was found among all four participants' accounts related to their sources of strength, what helped them become successful, and passing on this positivity to others.

4.4 Theme 3: Healing the Wounds: Sources of Strength, Success, and Helping Others

"I have gone through a lot of things in my life and my whole existence, my calling in life is to help others."

In reflecting on their school and life experiences, the participants provided examples and rich descriptions about how they were able to overcome hardships, gain strength, and experience success in their lives. For example, Madison spoke about some of the things that have helped her achieve success in school:

> High school was better for me since I spoke up and said "Hey I need help." We had teacher aides that would help me and some other people in my class. I would also go do work with the resource teacher. This helped a lot and I got caught up in everything. And I am going to go back to school and get my math upgraded 'cause I want to go to university. So I am happy about that. My mom also helped me be successful in school. She was always there and she helped me a lot. She would say, 'why be shy? There is no point to that.' She would always tell me that if I needed help to just ask. She also helped me a lot with my homework. Like she never graduated high school but she knew everything.

Brandon explained what has helped him within and beyond school:

> Well I know that they [his teachers] went to a conference and learned what FASD was and how to help students like me. So now they know what I have and how to help me better. I also go to a youth group and we play games and take camping trips. My E.A. [Educational Assistant] suggested it to me.

Teresa described what her sources of strength have been in school and in her life:

> In grade 11 I had an elective and I had to find a class to take and I am looking at this list of classes and I see drama, and this or that. And I remember thinking drama? Yeah right! But I signed up anyways. And looking back I've realized that drama saved my life. I got up on the stage and all of a sudden I could be whoever I wanted to be, I could laugh, I could flip out. I was allowed to do all those things and I am me today because of drama (laughing and smiling). It opened me up. Where I saw everything in a different light, because I didn't have to appear that way [depressed and unpopular] to people, I could be funny, I could be the popular one, I could be outrageous! And I was likable, I was even down right funny and I was awesome! I fell in love with drama and it changed everything for me. I became a different person. All of a sudden I had friends and I wasn't

> scared, you know, I wasn't hiding anymore, I didn't feel like a loser. It was like, I am who I am and I can choose to look happy on the outside and could hide the sadness and pain that was inside.

Derek discussed the organization that has helped him overcome the grips of drugs and alcohol:

> There was always EGADZ where I could just go dance and hang out. Me and my buddy were the tag team champions in Saskatoon we used to do back flips off the wall, break dancing you know. If it wasn't for EGADZ being there in my early upbringing I don't think I would be here today. So I really respect what EGADZ has done for me. And the elders in my life that were also there for me and said you know you can do it you can do it, you don't need drugs and alcohol.

Another commonality between participants was a desire to help others. Teresa explained how she continues to stay clean and sober and how she uses her story to help and strengthen others who are in the same place she was:

> I have been clean for a year and a half and I understand that if I am going through some miserable, horrible, hurtful, painful time…you know when the thought is in my head that, oh, I wish that I could just go and get high because this hurts right now. I just fast-forward it to okay, you went and got high, okay, so how does that feel? Seriously how does that feel? It will always feel much worse than what I am feeling at that second if I make the choice to get high and so, you know, that is what is keeping me clean. I have the option, you know, I always have the option, like this second I could go get high but I won't because I know where I would end up. I would be on the street and I would probably die, you know. I don't want that. I am here because everything happens for a reason. I am here not to overdose, not to get raped and killed, not to be on the street. No! That is not the reason that I have gone through all of this pain! I am here to survive all of this and to turn it around to help other people. That is what every single moment of my life is about. To grow me, to strengthen me, and in turn to strengthen others. I have chaired meetings at [an addictions center], in the past I have been in and out of [an addictions center] myself trying to get clean. I told those people there my story and I didn't hide anything because those people needed to know that is where I was and that is where I almost ended up, but I didn't and look at me today. It is possible you just have to get sick and tired of being sick and tired.

Derek explained why he wanted to share his story as a participant in this study:

> Well, just me having knowledge of FASD, FAS, FAE 'cause I have lived with it my whole life. And if somebody else could use the information that I provide to help others like me then I would like to share my experiences and get them out there. 'Cause people

> want to get information about Fetal Alcohol Disorder. It's a misunderstood disorder and I would like to share my story and my view on it.

Both Teresa and Madison explained how they have gained strength and insight about themselves through the experience of being diagnosed. Here Teresa discussed how she came to forgive her birth mother for drinking while she was pregnant with her and the clarity, strength, and purpose this brought to her life:

> When I think of my mom drinking with me I get so angry at her. How could she do this to me? It hurt me for a long time and I held a lot of anger inside for a really long time. But one day I came to realize that I just had to forgive her to move on with my life. And I think that one of my greatest accomplishments in life was being able to forgive her for doing this to me. This helped me realize that I do have a purpose in this world, I refuse to be labelled by anything because I know that I am capable of anything I put my mind to. I might have some definite struggles but really who doesn't? I have survived against a lot of odds and here I am, I will make a difference!

Madison explained how she is not defined by her diagnosis:

> For the longest time it [her diagnosis] bothered me, but I have overcome a lot of things in my life and I can honestly say that I am not ashamed of it and I accept that this is what I have. But it is not all that I am, you know? It doesn't define me as a person. I am more than partial FAS.

Despite all the struggles that the participants have confronted, they each found sources of strength and experienced success in their lives. For Madison, it was her mother who provided her with the courage to speak out and ask for the help that she needed. Once she was able to ask for help, her teachers were more than willing to provide it for her and she was able to experience success in school and graduated. For Brandon, it was his youth group and the responsibility that his teachers undertook to learn more about his diagnosis that helped him. In Teresa's case, it was drama class that provided her with the opportunity to freely express herself without fear of being harassed or teased. Investing in drama class allowed her to form friendships and provided a release from some of the pain from her childhood. Teresa also used speaking at an addictions center to fulfill her calling to help others who are going through similar situations. Finally, Derek credits EGADZ, a local youth support organization, and the elders in his life with his sobriety and success today.

4.5 Summary

The experiences shared in this chapter reveal some of Derek, Madison, Teresa, and Brandon's experiences of living with a Fetal Alcohol Spectrum Disorder and the hardships and successes that were experienced along the way. Several themes were identified in the stories of the participants. The first theme centered on the negative school experiences that each participant discussed. Each participant described a sense that they did not belong and were outsiders at school. Three out of the four of the participants described getting into trouble at school. These negative school experiences often led to participants' anger and frustration towards their diagnosis. The second theme focused on intergenerational alcoholism, child abuse, and drug addiction. Derek, Madison, and Teresa spoke about their experiences with intergenerational alcoholism and how this shaped their views and behaviour towards drugs and alcohol. Derek and Teresa also discussed the physical and emotional abuse that they experienced growing up and how they both used drugs and alcohol to numb the pain they were experiencing. The third and final theme centered on positive experiences related to sources of strength, success, and helping others.

Despite the hardships these participants have faced, they have each found sources of strength and success that have made them resilient in the face of adversity. The last chapter discusses these sources of strength and success in connection with existing research, the practical implications of these findings, the limitations and strengths of the current study, and areas for future research.

CHAPTER 5: DISCUSSION

This basic interpretive qualitative study was conducted to understand more about the school and life experiences of individuals diagnosed with a Fetal Alcohol Spectrum Disorder. This study also focused on resiliency and what has helped these individuals achieve success in their lives. The researcher had no preconceived notion or definition of what success was, but instead allowed the participants to determine what achieving success meant individually for each of them. For some, this was finding their sobriety, and for others, this was going onto receive post-secondary education. This chapter reviews and summarizes the main findings of this study, and extends the findings to related literature in the areas of: Fetal Alcohol Spectrum Disorders, resiliency theory, and the educational and life experiences of those with FASDs. Implications for educators, the strengths and limitations of the current study, and areas for future research are outlined.

5.1 Summary of Findings

Although the participants came from different ethnic backgrounds (i.e., Aboriginal and Caucasian) and social classes (i.e., low and middle socioeconomic status) the challenges they faced in both school and life were similar. The purpose of this study was not to understand their experiences through the filter of ethnicity, but instead to understand the common educational and life experiences of adults with Fetal Alcohol Spectrum Disorders. The experiences of Derek, Madison, Teresa, and Brandon were brought to life through their touching stories. Although the participants' experienced numerous difficulties in school, anger towards their diagnosis, intergenerational alcohol abuse, and emotional, physical, and drug abuse each person was able to overcome these adversities and experience success, resiliency, and even help others along the way.

The first theme, "I don't fit in": negative school experiences lead to anger and frustration toward diagnosis, related to how Derek, Madison, Teresa, and Brandon all experienced difficulty making friends, bullying, and getting into trouble at school. For example, Derek explained how he had to avoid fights with the bullies at his school. He also stated that he was a follower and would do what others told him to do because he wanted to make friends. Madison, Teresa, and Brandon also revealed that they felt like outcasts in school and did not really fit in. Another commonality that all participants discussed was getting into trouble at school. For example, Derek and Teresa both described themselves as the class clown and how they often got into

trouble for this behaviour. Difficulty understanding school subjects was also another common experienced shared by all the participants. Derek, Madison, and Teresa spoke about having difficulty grasping mathematical concepts. Most of the participants also spoke about receiving help from a resource teacher, educational assistant, or taking modified classes in order to graduate. These negative experiences in school often led the participants to become angry and frustrated with their diagnosis. For example, Brandon explained how he sometimes feels angry because he cannot do most things others his age can. Teresa also expressed anger towards her birth mother for drinking while she was pregnant. However, Derek chose to look at his situation positively and accept his diagnosis because he realized that it is not going to change and therefore he must learn to live with it.

The second theme centered on intergenerational alcoholism, child abuse, and drug addiction. Derek, Madison, and Teresa each spoke openly about a family history of alcoholism. For example, Derek described his experience of growing up with alcoholic and physically abusive parents. Teresa also discussed her history of abuse at the hand of her adoptive mother and her alcoholic birth father and mother. Although Madison did not experience abuse growing up, she did discuss her mother's recovery from alcoholism and the alcoholism that remains in her family. This early exposure to family alcoholism, and in some cases physical and emotional abuse, changed how the participants viewed alcohol and drugs. For example, Derek, Madison and Teresa all experimented with alcohol at an early age. Unfortunately, this led Derek and Teresa to experiment with drugs, to which they became almost instantly addicted. Teresa also discussed her promiscuity in relation to her alcohol use, which then led to prostitution when she began using and abusing drugs.

The participants in the current study were able to overcome their drug and alcohol addictions and found sources of strength, ways to achieve success, and the desire to help others in similar situations. The third and final theme, healing the wounds: sources of strength, success and helping others, focuses on the participants' positive experiences related to overcoming significant adversity and becoming resilient and successful individuals. For example, Madison explained how her mother taught her to stand up for herself if she needed help in school. This advice allowed Madison to receive more help from her teachers, and she was able to catch up in school and eventually graduate. Brandon also mentioned that his teachers helped him to achieve success in school. His teachers took it upon themselves to attend a conference about Fetal

Alcohol Spectrum Disorders in order to better understand Brandon and make appropriate accommodations which allowed him to succeed. Both Brandon and Derek recognized that another source of strength and success for them has been attending a youth group or youth center. Derek even stated that if it were not for the youth center EGADZ, he would not be here today. He also credits elders within his community with helping him stay clean and sober. For Teresa, attending drama class and acting had a significant positive impact on her life. It facilitated the development of new friendships and helped her to deal with the pain of being abused at home. After she got off the streets and stopped abusing drugs and alcohol she began acting again which helped her maintain her sobriety. Another commonality between participants was a desire to use their stories and experiences to help others in similar situations. For example, Teresa has given talks at different addictions centers around Saskatoon, which brought her a sense of purpose and meaning in her life. She also has plans to become an addiction therapist where she can use her experiences to uplift and help others who are struggling like she was. Finally, both Madison and Teresa explained how they have gained strength and insight about themselves through the experience of being diagnosed with a Fetal Alcohol Spectrum Disorder. Madison described how she is not defined by her diagnosis and confidently states how she is much more than someone with partial FAS and Teresa discussed how she came to forgive her biological mother for drinking during her pregnancy and the strength, purpose and meaning this brought to her life.

5.2 Integration of Findings with Existing Literature

The findings from the current study apply to Fetal Alcohol Spectrum Disorder literature that explores individuals' educational and life experiences and also the sources of strength that have enabled these individuals to experience success and resiliency. The three main commonalities identified in the stories of the participants are discussed further and linked with existing research literature in the areas of: (1) school related difficulties, (2) abuse, addiction, and prostitution, and finally, (3) Fetal Alcohol Spectrum Disorders and resiliency.

5.2.1 School related difficulties. Prenatal alcohol exposure clearly causes brain damage and is therefore associated with a host of learning, behavioural, and academic problems (Green; 2007; Saskatchewan Learning, 2004). The damages to the brain caused by prenatal alcohol exposure may be manifested through immature social and reasoning skills, difficulty generalizing information from one situation to another, memory difficulties, impulsive and

hyperactive behaviour, distractibility, difficulty processing sensory information, poor fine and gross motor skills, difficulty understanding the consequences of actions, and the display of poor planning and listening skills (Government of Canada, 2007; Green, 2007; Saskatchewan Learning, 2004). These numerous cognitive, behavioural, and adaptive skill difficulties which are common in those diagnosed with Fetal Alcohol Spectrum Disorders, may be the reason the participants in the current study experienced difficulty understanding school subjects.

In the current study, three participants spoke about having difficulty understanding school subjects, especially mathematics. Difficulties grasping the concepts presented in school, understandably lead participants to become frustrated with school. Teresa recalled her frustration with math and exclaimed, "I wanted to get it and I wanted to learn." The characteristics, strengths, and difficulties individuals diagnosed with Fetal Alcohol Spectrum Disorders demonstrate are individual and unique. Her comment reveals that educators must consider individual strengths and needs when teaching students with Fetal Alcohol Spectrum Disorders. One area educators may need to supplement for students with prenatal alcohol exposure is the teaching of mathematical concepts, an area that seems to be a major concern. For example, Duquette and Stodel (2005) interviewed eleven parents and seven children diagnosed with FASD and asked them about their school experiences. Parental responses indicated that all of the children who were still in school experienced difficulties in math. A second area educator may need to consider is the unique learning styles of individuals with FASDs. Teresa's comment also reveals that students with FASDs may want to learn but do not always have the tools to do so. Therefore, instead of labelling these students as lazy or slow we need to try and teach them in different ways so they can understand, learn, and achieve success both inside and outside of school.

Once students with FASDs do experience success and find something they enjoy, inside or outside of school, their self-esteem increases. This then allows them to adapt better to other situations they are presented with in their lives. This is exemplified when Teresa discovered drama, Brandon made friends through sports, and Derek honed his break dancing skills at EGADZ. Although each of these experiences were very different, they allowed the participants to achieve success in a certain area. In each case, these successful experiences allowed the participants to form new and lasting friendships which in turn fostered resiliency and increased their self-esteem.

Participants in the current study also noted behavioural and or emotional problems, which often got them into trouble at school. As Derek explained, "I was hyperactive like I said before so I was sent outside to the hallway a lot…being out in the hallway was also not good for me. I felt like an outcast." The behaviours that led the participants to get into trouble were often related to their diagnosis (i.e., hyperactivity and gregariousness); also these characteristics are often the most disruptive to the classroom. This experience is common among students with FASDs. Duquette and Stodel (2005) also noted that five of the seven participants exhibited behaviour problems in school. Specifically, parents reported that two students were disruptive, one was aggressive, and two experienced emotional difficulties (Duquette & Stodel, 2005). Individuals with prenatal alcohol exposure present with a variety of behavioural issues including hyperactivity, aggression, inappropriate sexual behaviour, delinquency, and self-injurious behaviours (Green, 2007). This information is congruent with the current study's findings since two participants reported being disruptive in the classroom (i.e., hyperactivity), one also reported aggressive behaviour (e.g., fighting), and others discussed illicit drug use and promiscuity. Due to the common occurrence of these behaviours, educators must be aware that students with FASDs often display behaviours that can be potentially disruptive to the classroom setting. They must be prepared to deal with these disruptive behaviours from all students, not just those with FASDs, and find the most effective way to manage disruptions within their classrooms.

These behavioural and/or emotional concerns can also lead individuals with FASDs to experience difficulties performing adaptive behaviours and displaying appropriate social skills. For example, studies suggest that individuals prenatally exposed to alcohol are at a high risk for developing problem behaviours that often interfere with their participation in the home, at school, and in social environments (Riley & McGee, 2005). Since individuals prenatally exposed to alcohol have already been found to have poorer social skills than those who are not exposed to alcohol prenatally (Thomas, Kelly, Mattson, & Riley, 1998), if disruptive behaviours are also present this will further delay their social and adaptive skill development. All participants in the current study revealed difficulty forming and maintaining friendships, discussed how they often felt as though they did not fit in, and were often bullied at school. For example, Teresa stated, "I never felt like I really fit in because it was hard for me to relate to other people." Thus, the current study adds further support to what is already known about individuals prenatally exposed to alcohol having difficulty developing social and adaptive skills.

These common behavioural and/or emotional issues suggest the need for preventative interventions and counselling services for this population. Programs aimed at modeling appropriate emotional reactions, social skills, safety, and sexual health related issues should be provided for individuals with FASDs and may need to be modified to accommodate for their cognitive deficits.

Another reason that the participants in the current study may have had so many negative educational experiences could be due to a lack of knowledge about how to best support students' with Fetal Alcohol Spectrum Disorders (Ryan & Ferguson, 2006). Within the educational system, there has been a lack of systematic research on the needs of students with FASD or on the most effective educational strategies to use with these individuals (Ryan & Ferguson, 2006). One finding from the current study suggests that individuals with FASDs should be encouraged to find something they enjoy doing and they can do well. This could include something at school, like drawing, or an activity outside of school, like playing a musical instrument. Whatever the activity is the individual should be encouraged to keep honing his or her abilities and praised for his or her successes. Achieving success fosters the development of self-esteem and therefore, promotes success in students with FASDs is an important step that educators and those working with these individuals should be made aware of.

5.2.2 Abuse, addiction, and prostitution. The participants in the current study spoke at length about their experiences with promiscuity and prostitution, alcohol and drug abuse, and physical and emotional abuse. These dangerous behaviours and harmful experiences seem to be all too common for individuals with Fetal Alcohol Spectrum Disorders. For example, Massey (1997) used hermeneutic phenomenology to explore the lives of five women, between the ages of 18 and 30, who had been diagnosed with FAS or FAE. Extensive interviews were conducted with each woman to explore her experiences (Massey, 1997). Themes related to poverty, unemployment, prostitution, alcohol and substance use, sexual abuse, physical health, pregnancy, suicide, isolation, and inequality arose from the women's stories (Massey, 1997). Thus, the women in Massey's study shared many similar and painful experiences with the participants in the current study. For example, Teresa discussed her experience being abused by her adoptive mother:

> I hated Friday's, hated them, and I loved Mondays. Which is usually the opposite for most kids, but this is how I escaped my home. So school was my safe haven. School was actually where I got to be myself without getting hurt or punished or ridiculed and even if

> it was by the teachers it was proper punishment…well not punishment, but discipline. And it was safe at school.

This comment suggests that educators must be aware when there is a pattern like this occurring in one of their students. If a child is regularly worried about leaving school on Friday's or at the end of most school days, concerns should be raised and questions must be asked.

Individuals with FASDs are often put up for adoption because birth parents are sometimes incapable of caring for their children. However, not all mothers who prenatally expose their children to alcohol decide on adoption. In the case of Madison and Derek, their birth mothers decided to raise them while they were still battling their addiction to alcohol. As Madison explained in her interview, her mother quit drinking for her children but not before her children were taken away from her and put into foster care. Once her mother was able to prove she was clean and sober she was able to have her children back. This is an extremely common occurrence that children with FASDs are living with one or both parents who have addiction issues. Thus, those who work with individuals who have FASDs should be aware that these behaviours could be going on inside the home. If signs of alcohol or drug abuse are suspected, the appropriate authorities must be notified.

5.2.3 Fetal alcohol spectrum disorders and resiliency. There are a number of protective factors that promote resiliency among individuals with Fetal Alcohol Spectrum Disorders (e.g., stable home environment and nurturing and supportive caregivers). Although the participants in the current study faced a multitude of adverse situations, they all persevered and demonstrated considerable resiliency and success in both the school system and life in general. However, it is important to note that many individuals with FASDs do not display the resiliency and success that was shown by the participants in the current study. I believe one of the reasons aspects of resiliency and success were found within the stories of the participants in this study was due to the fact that participants were recruited from community agencies focused on helping individuals cope with the difficulties associated with FASDs.

Some of the experiences that allowed the participants in the current study to experience success and increase their resiliency included: help from knowledgeable and caring teachers, supportive caregivers/adults, and youth groups and centers within the community. These experiences were also reflected in the stories of the parents and individuals who participated in the study by Duquette and Stodel (2005). Duquette and Stodel (2005) found four factors that

contributed to a successful school experience for individuals with FASD, and three were similar to the experiences of the participants in the current study. The first similarity found was related to the appropriate programs and services, caring teachers, and support from parents. In this study appropriate programs and services were referring to specific accommodations for course work and the availability of educational assistants. All the participants in the current study spoke about having a teacher aide or attending the resource room for extra help with assignments. Most participants felt this extra help allowed them to get caught up in their work and to experience success in school. For example, Madison stated that she had the help of a teacher aide and also went to the resource room for extra help in certain subjects. She realized that this extra help made a difference and she was able to get caught up in all of her schoolwork and graduate high school. She now plans to go back to school and upgrade her mathematics so she can attend university with the hopes of becoming a social worker. Thus, the essential help educational assistants and resource room teachers provide should not be overlooked and should be made available to all students with FASDs.

Help from caring and knowledgeable teachers was another theme that participants in the current study noted as essential to their success in school. Similar to the participants in the current study, Duquette and Stodel's (2005) participants commented on the importance of teachers who are knowledgeable about FASDs. It is important for teachers to understand the characteristics of the syndrome and make appropriate accommodations for affected students. Although the participants in the current study did not articulate this importance as fluently, they recognized the significance of having knowledgeable and caring teachers as vital components to their success. For example, Derek revealed how the teachers at his school took the time to attend a conference on Fetal Alcohol Spectrum Disorders so they could learn more about his disorder and understand how to best help him.

Another experience that helped the participants in the current study achieve success was the help of supportive parents and community members. In this case, parental support was viewed as giving advice and coaching the participants through certain situations in life. For example, Madison revealed that her mother taught her everything she knew which included how to become an advocate for herself at school. She attributes her educational success to her mother and her powerful words of encouragement. Similarly, Duquette et al. (2006) found that parental support and advocacy contributed to persistence in high school and experiencing success in

school among students with FASDs. Derek also revealed how the advice and wisdom from certain Elders within his community have allowed him to gain sobriety and become successful in his life. Clinical observations have revealed that caregivers and families are the primary advocates for individuals with FASDs throughout their lifetime (Olson, Oti, Gelo, & Beck, 2009). Therefore, in order to increase the likelihood that individuals with FASDs experience resiliency despite significant adversity, it is vital that high quality care giving and supportive and stable home environments are the focus for interventions. Caregivers who are clean, sober, and have the ability to advocate on the behalf of individuals with FASDs, will have the strongest positive impact on these individuals.

The participants in this study had resilient attitudes that were powerful, bold, and often selfless. For example, Teresa revealed why she believes she is here today and how she uses her story to help others who are struggling with addiction, "I am here to survive all of this and to turn it around to help other people. That is what every single moment of my life is about. To grow me, to strengthen me, and in turn to strengthen others." Neenan (2009) states that many factors affect the development of resilience, however, the most important one is the attitude individuals adopt to deal with adversity. Therefore, he suggests that attitude is the heart of resilience. I believe that the resilient attitude Teresa was able to cultivate is the reason she was able to overcome her addiction to drugs and alcohol, deal with the pain from years of repeated abuse, and is now entering a post-secondary program to become an addictions counsellor. She refuses to be labelled by her diagnosis and has proved that she is capable of anything she puts her mind to. Madison also revealed a similar resilient attitude when she stated that although she is not ashamed of her diagnosis it does not define who she is as a person. She powerfully stated, "I am more than partial FAS."

A final experience that contributed to the resiliency of the participants within the current study was their attendance at youth programs and community centers. Both Brandon and Derek explained how their involvement with youth programs and centers allowed them to make friends. In Derek's case, he credits his sobriety and success in life to a local community center he attended as a youth, "If it wasn't for EGADZ being there in my early upbringing I don't think I would be here today. So I really respect what EGADZ has done for me." These positive experiences reveal that individuals with FASDs should be encouraged to join a youth program or attend a youth center that they enjoy in there community. These programs and centers may

allow youth the opportunity to form friendships with peers with similar interests. Youth with FASDs often experience difficulty with social skills and these programs offer additional opportunities for attendants to develop these vital skills. These centers also differ from the educational environment and therefore, allow attendants to express themselves in other, often more creative ways, which may also contribute to friendship formation.

5.3 Implications for Helping Professionals

The current study raises issues that may be of interest to a variety of helping professionals working in school-based and/or community environments (e.g., educators, psychologists, counsellors, policy makers, etc). The results of this study provide insight into the educational and life experiences of four adults who reported being diagnosed with a specific FASD and therefore presents ideas and suggestions as to how helping professionals might intervene to meet the needs of these individuals. Four significant implications for helping professionals were raised by the current study: (1) the importance of teacher knowledge and education about FASDs; (2) the need for appropriate prevention and intervention programs that focus on the common difficulties individuals with FASDs face; (3) the importance of supporting and encouraging the strengths individuals with FASDs display; and (4) the need to help connect individuals with FASDs to youth centers and community programs.

5.3.1 Importance of teacher knowledge and education. The comments made by the participants in the current study reveal they are struggling in school. Thus, educators have a responsibility to find different ways to teach these students so they are able to understand, learn, and achieve academic success. It is a must for those working with individuals prenatally exposed to alcohol to have a greater understanding of what FASDs are, the damage that is caused to the brain, and the subsequent behavioural concerns that can occur as a result. It is my hope that through having this increased understanding, these students will no longer be labeled as slow or lazy, but instead viewed as having significant brain damage. This different outlook may increase patience when working with some of the behavioural challenges that are presented in this group.

Another important reality that helping professionals should be made aware of is the living environment to which many individuals with FASDs are exposed. Often children with FASDs are living with a parent or parents who have addiction issues. Thus, if signs of alcohol or drug abuse are suspected, notification of the appropriate authorities is required.

5.3.2 Appropriate prevention and intervention programs focusing on common difficulties. The common behavioural and/or emotional difficulties individuals with FASDs face suggest the need for prevention, interventions, and also possible counselling services for this population. Programs that focus on modeling appropriate emotional reactions, social skill development, information and concerns related to drugs and alcohol, family addiction issues, and sexual health should be provided to individuals with FASDs. Although many school-based programs and community programs on these topics already exist, the information in these programs may need to be modified to accommodate for the cognitive deficits experienced by these individuals. Therefore, a school counsellor or other willing professional could adjust the content of the information presented to ensure that individuals with FASDs understand this important information.

5.3.3 Supporting and encouraging individual strengths. One original finding from the current research suggests that individuals with FASDs should be encouraged to find an activity they enjoy doing and can do well. As previously stated, this could include something that is offered inside the school environment, like painting in art class, or an activity outside of school, like playing the piano. Whatever the activity, the individual should be encouraged to keep developing his or her skills and praised for his or her success and improvement. Achieving success can foster the development of self-esteem and therefore promote success in those with FASDs. This in turn fosters resiliency and can improve the outcomes in life for individuals living with Fetal Alcohol Spectrum Disorders.

5.3.4 Connecting to youth centers and community programs. As seen in the current study, youth programs and centers allowed participants the opportunity to form friendships with peers who had similar interests. Individuals with FASDs often experience difficulty with social skills. Therefore, these programs offer additional opportunities for attendants to develop these necessary and very important skills.

5.4 Strengths of the Current Study

There are four main strengths related to the current study. First, this study provides insight and understanding into some of the experiences of individuals affected with FASDs. Participants' stories further our understanding related to how their diagnosis affected their school and life experiences, social interactions, peer interactions, and how they coped with this diagnosis.

Second, this research provides educators and other helping professionals (e.g., counsellors, psychologists, etc) with information to benefit adolescents and children prenatally exposed to alcohol. The beneficial findings include: the importance of teacher knowledge and education about FASDs; the need for appropriate prevention and intervention programs that focus on the common difficulties individuals with FASDs face (e.g. difficulties with mathematics, disruptive issues, family alcoholism etc); the importance of supporting and encouraging the strengths individuals with FASDs display; and the need to help connect individuals with FASDs to youth centers and community programs. Professionals who employ intervention strategies with these individuals often do so with a limited understanding of what interventions these individuals have found to be most effective. Therefore, the findings listed above will hopefully be used by helping professionals in order to improve the outcomes of those with FASDs.

A third strength of the current study is the inclusion of participants from both Aboriginal and Caucasian backgrounds. The province of Saskatchewan has a diverse population. Although the focus of the study was not to compare the experiences of these two ethnic groups, their inclusion certainly adds to the strength of the study since it increases the studies' representativeness.

Lastly, and most important, few previous studies have focused on understanding the school and life experiences directly from individuals diagnosed with specific FASDs. Therefore, the results of the current study contribute to this small body of research and provide a more comprehensive understanding of the experiences of individuals diagnosed with this disorder.

5.5 Limitations of the Current Study

The first limitation is related to the characteristics and demeanor of a participant. One participant was less forthcoming with information during the interview and also struggled at times to formulate his ideas verbally. The fact that this participant was a teenage boy could have contributed to the noted lack of expansion when answering questions during the interview. For example, he often gave one-sentence answers and as a researcher I had to work hard to get him to expand on his thoughts. However, once he settled into the environment and became more comfortable with me, the depth of his answers did improve.

The second limitation of the current study involves the use of self-report data. This study focused on the educational and life experiences of adults with Fetal Alcohol Spectrum Disorders, therefore, the findings are based on the sole perspectives of the individuals. Self-reported data

may result in participants providing the researcher information from their perspective. Others who may be asked the same information about this individual (e.g., parents, teachers, siblings) may not see things in the same light as the individual. Often this is addressed in studies by interviewing the participants' parents, teachers, or siblings. However, in order to check that the information I did receive was as comprehensive as possible, I requested a second interview where the participants could add any new information that they may have left out from the first interview. As a researcher, I was interested in understanding the educational and life experiences directly from the individuals affected by FASDs, which is the reason only self-report data was chosen for a method.

5.6 Implications for Future Research

There are five main implications for future research based on the current findings regarding the educational and life experiences of those with Fetal Alcohol Spectrum Disorders. First, I believe that it is necessary to develop effective research-based interventions for individuals with FASDs. Future research aimed at developing programs (i.e., related to social skill development, drug and alcohol interventions, family addiction issues, and sexual health concerns) that can be modified to accommodate for the cognitive deficits of individuals with FASDs is greatly needed. Within the educational system there has been a lack of systematic research on the needs of students with FASDs or on the most effective educational strategies to use with these individuals (Ryan & Ferguson, 2006). Therefore, while the current study addresses some of the needs of students with FASDs, more research is needed on the most effective educational strategies that will promote learning and success within this population.

Second, the area of resiliency as it relates to individuals with FASDs needs to be further explored. The resilient attitudes of the participants in this study are remarkable and should be explored further. How did these individuals cultivate resilient attitudes in the face of such significant adversity? Some of the influences that contributed to the participants' resiliency in the current study were: support and advocacy from caregivers, knowledgeable and caring teachers, support and encouragement of positive skill development, and youth programs and community centers. However, there is still a lack of research that focuses on the mechanisms individuals with FASDs use to overcome adversity and increase their resiliency. This is vital information to have if we are going to try and improve the outcomes in life for those affected by FASDs.

A third area that future researchers in the area should be made aware is the challenges that were presented when working with this population. For example, participants often did not have a phone or computer and therefore my original attempt to recruit through posters became almost impossible. To overcome this challenge, I recruited participants through community organizations. Another challenge I faced after finding participants who met the necessary criteria was scheduling interview times that the participants would attend. Mornings often did not prove to work well as interviews were often changed to later in the afternoon. This required great researcher flexibility and commitment to complete the interviews.

A fourth focus of future research could be to compare and contrast the experiences of individuals with FASDs from different ethnic backgrounds. Although this was not the focus of the current study, future research that examines and compares the experiences of different ethnic groups can serve to enrich our knowledge about the experiences of those with this disorder and to my knowledge has not been completed to date.

A fifth and final suggestion for a future research study I would like to conduct involves performing a case study to explore the life of Teresa using phenomenology. She is of average or above average intelligence and therefore would be able to understand the more abstract concepts presented in phenomenological studies. Teresa was extremely articulate and spoke with much passion when telling her story. Although her life began with considerable hardships and misfortune, it has transformed into a story of triumph and resilience. I believe performing an in-depth phenomenological case study of Teresa's life would present a better understanding of how an individual is able to cultivate a resilient attitude in the face of such significant adversity.

5.7 Conclusion

In summary, the findings from this study demonstrated that it is important for helping professionals to have an understanding of FASDs and how prenatal alcohol exposure affects academic, behavioural, and social functioning. Helping professionals must also be aware of the living situations that many students with FASDs are exposed to (i.e., the history of substance abuse that is sometimes present). Students with FASDs also require appropriate educational interventions and the support of caregivers and teachers if they are to achieve success in the educational environment. Another finding from the study revealed that encouraging the development of skills that individuals are good at often increases self-esteem and feelings of successfulness, which in turn can help foster a resilient attitude. This resilient attitude is

beneficial in allowing the person to feel more capable and improves feelings of self-worth. Finally, youth programs and community centers were found to be beneficial to the participants in the current study as they encourage the development of social skills and meaningful relationships.

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APPENDIX A

CALL TO PARTICIPATE

Are you an individual who has been diagnosed with FAS, Partial FAS or ARND?

Would you be willing to discuss your experiences in confidential research interviews?

I, Lyndsay Knorr, am a graduate student researcher in Educational Psychology & Special Education at the University of Saskatchewan. I am interested in the school and life experiences of someone diagnosed with a Fetal Alcohol Spectrum Disorder (FASD). I am seeking volunteers to participate in one individual 60-90 minute interview and one follow-up meeting for my research study.

In order to participate, volunteers must:

A) Be between the ages of 18 and 30.
B) Be formally diagnosed with either FAS, FAE, Partial FAS or ARND.
C) Be willing and able to share their story of being diagnosed with a FASD in school and what their experience was like.
D) Not currently experiencing any immediate crisis.
E) Be a current or former high school student.

If you are interested in learning more about this study, please contact Lyndsay Knorr at 222-4134 and leave a message or email : lak475@mail.usask.ca

APPENDIX B

PARTICIPANT CONSENT FORM

You are invited to take part in a research study called "*The Unheard School and Life Experiences of Those with Fetal Alcohol Spectrum Disorders.*" Please read this form carefully and feel free to ask any questions you have.

This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on February 9, 2011. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

Researchers: Lyndsay Knorr (MEd Candidate) & Dr. Laureen McIntyre (Thesis Supervisor), Department of Educational Psychology & Special Education, University of Saskatchewan (email: lak475@mail.usask.ca, phone: 222-4134)

Purpose and Procedure: You are being asked to take part in one interview and one follow up meeting. This will give an understanding of how being diagnosed with a FASD affected your school experiences.

I want you to talk freely about your experiences. The first interview will be around 60-90 minutes. I will ask you if it is okay to record this interview. Later this interview will be written out word for word. Then you will be given a shortened copy of the interview to read at the follow up meeting.

The follow-up meeting will last around 45-60 minutes. The information from the taped recordings will only be heard by me and my supervisor. Your name and identity will be kept private by using a different name.

All interviews will be at a time and place that works for you. Participation in this research study is not part of your regular health care or medical treatment. You may decide not to participate at any time.

The findings will be used for my thesis. I might use these finding to write an article or talk about it at large meetings.

Potential Risks: Any risk for being involved in this study is low. Taking part in this study is your choice. You have the right to leave at any time.

It is possible that you may have some discomfort in talking about your experiences. At all times you are free to decide what you want to discuss. You can end a discussion or choose not to answer any question.

If you experience any bad feelings because of the study, here is a list of places you can visit/phone:

Saskatoon Mobile Crisis Intervention
Telephone: 933-6200

The Mobile Crisis Intervention Centre is a 24-hour telephone counselling service for individuals who are experiencing a crisis situation in their lives. The counsellors are willing to visit individuals in their homes if it is convenient.

Kids Help Phone
1 800 668-6868

Mental Health Services – Saskatoon Health Region
Suite 145, 122 3rd Ave. N.
Sturdy Stone Building
Phone: (306) 655-4100
Fax: (306) 655-4115

Catholic Family Services of Saskatoon
200-506 25th Street East
Saskatoon, SK S7K 4A7
Phone: (306) 244-7773
Fax: (306) 244-8537
Email: staff@cfssaskatoon.sk.ca

Family Service Saskatoon
102, 506 - 25th Street East
Saskatoon, SK S7K 4A7
Phone: 306-244-0127

Prairie Therapists and Trainers
910 Queens Street
Saskatoon, SK
SK S7N 0N2
Phone: (306) 665-6242
Toll-Free: 1-877-772-9933
Fax: (306) 664-2410

Potential Benefits: Talking about your experiences of being diagnosed with a FASD may be helpful to you.

Taking part in this study may also help us to better understand others who are also diagnosed with a FASD. This may also help teachers understand students with FASDs and allow them to teach better.

Confidentiality: The information from this study will be shared with the public. But your name will be kept private through the use of a different name.

This form will be kept separate from the information you give in the interview. Then it will not be possible to connect your name with any information you give. The interview tapes will also be known by a different name.

There is still the chance that you could be known to others because of the things you say during the interview. You can ask for parts of the interview not to be included in the thesis. At the follow-up meeting, you can look over the shortened interview and add, change, or delete any information you want.

Storage of Data: To protect your privacy, all the information from the study will be kept in a locked filing cabinet. After the study has ended the information will be kept for 5 years in a locked filing cabinet in Dr. Laureen McIntyre's office. After 5 years the data will not be needed and it will be destroyed.

Right to Withdraw: It is your choice to take part in the study. You can choose to only answer questions you want. You can also ask the recorder to be turned off at any time. You can leave the interview for any reason, at any time, without punishment of any kind.

If you do decide to leave the study, this will not affect your medical care or access to services. If you leave the study, any information that you have given will be destroyed.

Your right to remove your information will apply until the results have been turned into a completed document and made available to the public. After this it may not be possible to remove your information from the study.

Questions: If you have any questions about the study, please feel free to ask at any time. You are also free to call the researchers at the numbers provided below if you have questions later.

The complete study can be found by calling myself at 222-4134 or lak475@mail.usask.ca or by calling my thesis supervisor Dr. Laureen McIntyre at 966-5266.

Consent to Participate: I have read and understand the information above. I have been able to ask questions and my questions have been answered.

I agree to participate in the study described above, understanding that I may choose to leave this study at any time. A copy of this consent form has been given to me to keep.

_____	_____
(Name of Participant)	(Date)
_____	_____
(Signature of Participant)	(Signature of Researcher)

APPENDIX C

TELEPHONE SCRIPT FOR PARTICIPATION CRITERIA

R: Thank you for your interest in the research project. Now I just want to make sure that you are able to participate in the study. So first of all, are you between the ages of 18 and 30?
R: Are you diagnosed with FAS, partial FAS or ARND?
R: What was the process you went through to become diagnosed?
R: Are you willing to share your school experiences of being diagnosed with a FASD?
R: Are you in any sort of immediate crisis? (experiencing anxiety, depression, loss, break-up?)
R: Have you attended high school?
R: Great, now that we have covered that, I would like to set up a time to meet and hear about your school experiences. I have a room in the Murray Library at the U of S campus that we could book; do you require directions and/or bus tickets in order to meet? Or if it works better for you we could meet at a community agency your familiar with.
R: Great, thank you for your interest in the study and I will call you back if you are chosen for an interview.

APPENDIX D

INTERVIEW GUIDE

Questions for First Interview:

1. What made you want to take part in this study?
2. Describe what elementary and high school was like for you? Did you like it?
3. What did a good day look like for you in school?
4. What did a bad day look like for you in school?
5. Would you say school was a positive or negative experience overall?
6. Why? What made you feel this way?
7. How was it making friends in school?
8. What made it so?
9. How did you find getting along with different teachers?
10. When were you diagnosed with (FAS, Partial FAS, or ARND)?
11. How did you react when you found out about your diagnosis? (angry, relieved, shocked)
12. How did your parents or guardians react to your diagnosis?
13. Did your life change in any way after you were diagnosed or learned about your diagnosis?
14. Did things at school change?
15. Did your thoughts about yourself change after you were diagnosed or you learned about your diagnosis?
16. What has your experience of being diagnosed with (FAS, partial FAS, or ARND) in school been like?
17. What are some things that have helped you be successful in school and life?
18. What things have not helped?

Questions for Second Interview:

1. After looking over the shortened version of the interview and your quotations is there anything you have thought of that you would like to add, change, or delete?
2. Have you had any new thoughts or ideas since our last interview?

APPENDIX E

DATA/TRANSCRIPT RELEASE FORM

Overcoming Adversity: The Stories of Four Resilient Adults with Fetal Alcohol Spectrum Disorders

I, _____, have reviewed the final transcript and quotations from my personal interviews in this study, and have had the opportunity to add, change, and delete information from the transcript and my quotations. I acknowledge that the information accurately reflects what I said in my personal interviews with Lyndsay Knorr. I hereby authorize the release of this transcript and my quotations to Lyndsay Knorr to be used in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my records.

_____	_____
Name of Participant	Date
_____	_____
Signature of Participant	Signature of Researcher