

**The Experiences and Needs of Young People with FASD:
Silenced Voices from Youth in Care**

By

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Dedication

This research is dedicated to “Little white dove that flies free” and all children and youth in care.

Abstract

This research explores the experiences and needs of five young people with FASD in care. Data was gathered through personal interviews with youth in care, guided by an anti-oppressive research philosophy. The findings suggest that youth in care with FASD experience a myriad of challenges throughout their journeys in care with regard to placements, caregivers, and the transition to adulthood for which the impact for young people was difficult to understand. The high degree of secondary disabilities of FASD was found to be alarming in this group of young people. The study also found that those with more of an awareness of their disability had the capacity to speak to some of their support needs. All of the youth revealed strengths within themselves and reported having goals and dreams for their futures. A number of recommendations, which include input from participants, are highlighted, with the intention of providing some suggestions for best practice with our young people with FASD in care and policy changes within the systems working with this population.

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Chapter 1

Introduction and Rationale

This experience we did not choose, we would have given anything to avoid it. Yet, it has made us different. It has made us better. Through it, we have learned the lesson that no one studies willingly, the hard, slow lesson that one grows by suffering.

Clara Claiborn Park, 1990

Although we have been aware of the effects of prenatal alcohol exposure for over 30 years now, we continue to struggle as a society with preventing, intervening and managing Fetal Alcohol Spectrum Disorders (FASD). FASD is a ‘life journey disability’ that challenges children, adolescents and adults and their caregivers, throughout the life span. As a result of the high level of care that these individuals require and the challenges they pose to caregivers, they are often moved out of their birth and adoptive homes, into the care of the child welfare, mental health and justice systems.

Adolescents affected by FASD are a special group of youth that often find themselves in care. Besharov (1994) estimates that 80% of alcohol affected children enter into and grow up in the child welfare system before they are five years old and never return to their family of origin. After eighteen challenging and rewarding years of front-line youth care and social work with these clients, I continue to be in awe of the complexities and uniqueness in each individual person with FASD. I have noticed that young people with this disability, whether diagnosed or suspected, continue to be misunderstood and misread by those around them which leads to them constantly finding themselves in trouble. Anecdotal evidence suggests that adolescents with FASD tend to be labeled as a ‘behavior problem’, their difficult behaviors perceived as ‘willful misconduct’, and frustrated caregivers and professionals tend to punish with traditional,

inappropriate and sometimes, harmful interventions. Dubovsky (2006) has coined the term NURMU to describe how young people with FASD are often viewed by caregivers and professionals. NURMU stands for non-compliant, uncooperative, resistant, manipulative and unmotivated. Unfortunately, I have been witness to countless occasions where youth and adults with FASD have been labeled as NURMU by caregivers and professionals. The catalyst for this research is the spectrum of emotions that I feel each day working with and advocating for young people with FASD and their families and the commitment that I have to social change for this marginalized group.

Many individuals with FASD are not well understood by their caregivers due to the caregiver's limited knowledge about the disability, their lack of specialized skills in caring for this population of children and the (multiple) system's lack of response and resources. There is a standardized way of caring for children in care and the system does not recognize the unique needs of children unless they are observably disabled and identified as such. Many children and youth with FASD are not identified and those that are, often do not have physical signs of a disability and are treated the same as typical children. Further, if they are placed in a regular placement, then they are cared for by regular staff that does not have specific training in FASD to accommodate their needs. When I started my youth care career in 1992, I was one of those well-intentioned youth care workers who did my best to take care of and educate the children in my care, and was ill equipped to do so. My co-workers and I made many mistakes while working with children affected by FASD, which likely contributed to their perpetual feelings of failure, 'inability' to be of good behavior, and the perpetuation of secondary disabilities, such as mental health issues, drug and alcohol misuse and law involvement. Sadly, in my years

of work with this population, I have experienced the loss of many of these youth to suicide, murder or the street. In the past several years, I have really concentrated my efforts on trying to understand more about what is happening for people with FASD and how we can better intervene. I have taken courses and a myriad of workshops, specializing in the issues related to FASD. I have worked as a Community Facilitator of the FASD Youth Justice Project at the Manitoba Youth Center (MYC) and attempted to assist those working in the Justice System to become more FASD-friendly by providing information sessions and training to correctional officers as well as appearing in court for youth with FASD. As well, I have provided clinical consultation to staff who works with youth with FASD in care at Macdonald Youth Services (MYS) and also provided 1-1 counseling to those youth in care. Additionally, I co-facilitated FASD training for the staff and management of MYS. Finally, in the eight years that I have been working on this project, I have been reading and researching about FASD and learning more every day about the intricacies of the disability from those that live with it.

I continue to be concerned about the care that these youth are receiving and I seek to facilitate change in the lives of these young people whose voices have been silenced. I was interested in exploring the experiences and needs of adolescents with FASD who are currently or have previously been in care by delving into the topic with a group of young people living with FASD. The aim was to have their voices heard throughout the research and have the 'experts' involved in the research as much as possible. Frankly, this research is for them and my hope is that they and others that follow them benefit from this research.

Rationale

The responsibility and obligation to youth in care lies with the professionals and caregivers employed by and working with child welfare agencies, mental health facilities and justice departments and for some youth, their families. Youth with FASD are among the faces of those in care, yet they are often invisible and they are being failed by the system. Lack of knowledge, skills, support and services to these youth translates into the secondary disabilities of FASD in adolescence and further difficulties into the “lonely” transition to adulthood. The system is overloaded, caseloads are too high to provide adequate service and it is rare to be provided specialized and FASD-friendly care within the systems’ settings.

The research in the existing literature regarding the experiences of young people with FASD in care from the perspective of the young person is very limited. However there are some important contributions to note. Deborah Rutman’s research (1996) on the experiences, needs and support strategies of young adults with FASD includes some of the experiences of those with FASD in care as they do speak of their experience with social services. Also, Rutman, LaBerge, and Wheway (2005) explored the challenges, strategies and supports of young adults with FASD in regards to parenting, involvement with the law and employment, which included talk of experiences with child welfare. Probably most parallel to the current study is the research conducted by the Child and Youth Officer for British Columbia (2006) who undertook a study that explored the transition from care of youth with FASD who were considered high risk to live independently. In this study, the youth as well as their caregivers and professionals working with the youth were interviewed and surveyed about the experience and

important recommendations were highlighted. Other studies (Fuchs, et al, 2006; Gough & Fuchs, 2008) have looked at some of the factors regarding the transition to adulthood for these young people. However, the voices of the youth are not included in those studies.

Alongside this gap in the research literature are the limited number of FASD-specific support programs and services for adolescents with this disability in our province. Much of the funding for FASD focuses on prevention with some services available for age 0-6 children and their families. The most challenging difficulties begin to appear in early adolescence with youth experiencing multiple placement breakdowns (living arrangements and school placements) and the acceleration of secondary disabilities. This is normally the time in one's life in which there is progress in endeavors, a hint of maturity and a move towards some degree of independence. This is often not so for these youth. Traditional societal expectations abound at this critical time and due to the pull of the disability, expectations often cannot be met. At the same time, supports and services are unavailable, risk factors related to the disability increase and protective factors decrease. It is this void in service and in existing research on this topic that brings marked significance to this study. The purpose is to shine the light on this group of youth who are submerged in a system that often does not know how to respond. The hope is to hear the voices of these young people, have them shed some light on the experience of being in care and also explore the needs expressed by the experts, those living the experience. This study contributes to knowledge in the field of FASD due to the limited amount of first hand knowledge brought to the FASD research and also the unique ideological and methodological framework used. Research facilitated with the

contribution of young people with this disability is a much needed addition to our FASD bookshelf. From an anti-oppressive research perspective, collecting data through personal interviews and thematic analysis, this study explored the experiences of youth with FASD in care. Recommendations were co-formulated with the young people for child welfare policy and practice based on the findings from the data analysis.

Within this thesis, I review the literature on the topic, explore current and related research and examine some of the gaps within the literature. I describe the details of the research methodology, from methods and data analysis to ethical considerations.

Finally, I discuss the evaluation of the research, limitations and strengths, the key themes that emerged from the interviews, and discussion and recommendations for best practice and policy changes.

Chapter 2

Literature Review

Introduction

The intention of this literature review is to define and explain the term FASD and the diagnoses that fall under the FASD umbrella. A general description of the stage of typical adolescence is included and then the experience of FASD in adolescence follows. I provide information regarding the primary and secondary disabilities associated with FASD and the universal protective factors related to secondary disabilities. I outline some statistics on prevalence rates regarding FASD in general and FASD related to youth in care. An exploration of the research on the specific topic and related areas will be highlighted, followed by noting the gaps in the literature and concluding with an explanation of why this particular project is significant.

Part 1: What is Fetal Alcohol Spectrum Disorder (FASD)?

Fetal Alcohol Syndrome (FAS), first identified in 1972, is caused by prenatal alcohol exposure and characterized by growth deficiency, a specific pattern of facial features, and signs of central nervous system dysfunction (Streissguth, 1997). The broader term of Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term, coined in recent years to encompass the wide range of adverse effects of prenatal alcohol exposure—from the classic FAS to its more partial presentations. The term FASD is not a diagnosis. According to Chudley et al (2005), the current diagnostic criteria in Canada for FASD include the following medical diagnoses: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (pFAS); Alcohol Related Neurodevelopmental Disorder (ARND);

Alcohol Related Birth Defects (ARBD). Individuals with FASD may exhibit physical, mental, behavioral and learning difficulties with life long implications.

Although the etiology of FASD is clearly the toxic effect of prenatal alcohol exposure on the developing fetus, epigenetic studies have shown other possible confounding factors in the cause of FASD. The developmental and neuropsychiatric clinical presentation of this teratogenic effect has been shown to be affected by genetic factors which modulate a woman's susceptibility to having a baby with FASD (O'Malley, 2007). O'Malley (2007) describes medical factors of the mother for example, chronicity of alcoholism, general nutritional status and her genetic endowment as factors. He also notes environmental factors such as early abandonment, multiple living placements and exposure to sexual and physical abuse as confounding factors. Haycock (2009) suggests that the FASD spectrum should be expanded to include pre-conceptual effects such as socioeconomic factors, maternal malnutrition and other potential confounders in the cause of FASD. The possibility that ethanol consumption prior to conception may induce epigenetic abnormalities in the germ line has major public health implications and requires urgent attention (Haycock, 2009).

As stated earlier, FAS includes a pattern of classic facial features, growth deficiency, and signs of central nervous system (CNS) or brain impairment. Partial FAS includes some of the classic facial features and/or some growth deficiency and CNS impairment. A diagnosis of ARND requires an individual to have signs of CNS impairment with no classic facial features and no growth deficiency present. Finally, ARBD refers to the congenital anomalies or birth defects caused by prenatal alcohol exposure (Streissguth, 1997).

The area of most significance in the diagnosis of FASD is the CNS damage and the subsequent neurobehavioral difficulties. In the assessment of CNS impairment, nine brain domains are assessed. They include: hard and soft neurological signs including sensory integration; brain structure (including microcephaly); cognition (including I.Q.); communication and language; academic achievement; memory; executive functioning and abstract reasoning; adaptive behavior, social skills and social communication; attention span, activity level, and distractibility (Schwab, 2009). Three or more brain domains need to be assessed as severely impaired (2 standard deviations below the mean) in order to receive an FASD diagnosis. The CNS damage is the critical piece explored within the FASD assessment, whereby the abilities and disabilities of the person affected are determined. This is the place where appropriate interventions can be implemented and adaptations can be made based on which brain domains have been affected.

In adolescence, the most common diagnosis given is ARND (Chudley, personal communication 2005). ARND is often called an 'invisible disability', due to the hidden brain impairment and no obvious physical signs on the person. Having an invisible disability places a person at higher risk because they appear to be a typical teenager and are treated accordingly and expectations are parallel to that of a typical teen. The organic brain damage is variable and unpredictable and can be as severe as in a person with a diagnosis of FAS (Streissguth, 1997). The long term prognosis for individuals with ARND is poorer than for those with FAS and partial FAS because of the invisibility of the disability (Streissguth, Barr et al., 1997).

For the purposes of this research, the following terms were used: FASD or any of the diagnoses under the umbrella, Fetal Alcohol Effects (FAE), alcohol affected or

alcohol exposed. Many people have not caught up to the newer terminology and might still understand this disability as we did years ago. Some might have a diagnosis of FAE from years ago. Others may suspect FASD, but not have a diagnosis, and might say that a person who was exposed to alcohol during pregnancy is “alcohol affected” or was “prenatally exposed to alcohol”. Participants in this project did not need a formal diagnosis to participate, but were young people who identified as having been exposed to alcohol prenatally.

FASD in Adolescence

Adolescence is one of the most challenging and confusing stages of one’s life. Physical, cognitive and psychosocial changes occur at this critical time and at a rapid pace in the typical development of an adolescent. The onset of puberty brings physical and sexual development changes in adolescents with variable expression and timing. At the same time, there is great diversity in cognitive development at this stage. Some adolescents are still in the ego-centric stages of pre-school and others reach the stage of abstract thinking. As young people begin to search for and try on their identities, practice maturity, a myriad of relationships and independence, these psychosocial factors present with even more diversity (Berger, 1999). Those with basic needs unmet from an early age and inadequate support and education through childhood, have more difficulty in adolescence. This group of youth might have troubles with school, addictions, law involvement, mental health issues and difficulty with interpersonal relationships.

The adolescent years are extremely challenging for children with FASD and for their families, especially for those children who have not been diagnosed (Streissguth,

1997). Malbin (1993a) states that parenting children with undiagnosed FAS/FAE, is like trying to find your way around Cincinnati, using a road map of Denver. Whether the youth is diagnosed or not, caregivers of adolescents with FASD notice that their child is not “catching up” developmentally and at the same time the expectations placed on them socially, emotionally, cognitively etc., are the regular standards expected of typical teens. In our society, ‘growing up’ is often associated with more freedom, independence and less adult supervision, of which the price is responsibility. This responsibility presents significant difficulties for adolescents and young adults with FASD (VON Canada, 2005). With unrealistic expectations placed on developmentally younger adolescents with FASD, the consequence is often damage to their self-esteem, mental health, social situation, school performance, living arrangements and physical health. Diane Malbin (2000) coined the term ‘dysmaturity’ to explain behaviors displayed by youth and young adults with FASD that are more commonly seen in younger children. ‘Dysmaturity’ is considered completely normal for a person with FASD who functions at a developmentally younger age due to having been exposed to alcohol prenatally. Support through adolescence is essential in order to prevent the ‘cycle of deterioration’ associated with FASD (Malbin, 1993a).

Youth with FASD who are not with their families and/or communities because they are in care are at even higher risk for attachment and identity issues tacked on to the secondary disabilities that might also be occurring. Adolescence is a critical time for appropriate interventions to be implemented in order to stop the occurrence or slow down the progression of secondary disabilities into adulthood, when there is even less support for this group of young people. The transition to adulthood for youth in care with FASD

is a frightening and confusing time when the 'state' ends their parenting duties and the youth is expected to go it alone. Many youth with FASD whom I have worked with have felt that the only solution at that point, is to end their lives. Shibley & Newton (2006) found that young people in care with FASD had a considerably higher rate of mental health issues than their non-disabled peers and that FASD was a factor in the majority of deaths of young people by suicide. Also, of those youth completing suicide, most were found to have completed suicide at the age of 17, which signals the impact of the crisis for young people aging out of the child welfare system (Shibley & Newton, 2007).

Primary and Secondary Disabilities of FASD

The primary disabilities of FASD are the neurological deficits that a person with FASD is born with. Secondary disabilities refer to those difficulties that a person with FASD is not born with, that could presumably be ameliorated through better understanding and appropriate interventions (Streissguth, 1997). In a longitudinal study by Streissguth (1997), secondary disabilities among this population of adolescents and adults were abundant:

95 % had mental health problems

55 % confined in prison, mental institutions, or addictions treatment centers

52 % had inappropriate sexual behaviors

60 % had disrupted school experiences

60 % had trouble with the law

50 % males and **70 %** females had alcohol or drug problems

82 % were unable to live independently

70 % had difficulty with employment.

Secondary disabilities can be diminished with adequate care, understanding, support and advocacy from an early age. It was once thought that secondary disabilities began presenting as an issue in adolescence, however, anecdotal evidence suggests that they are emerging in earlier childhood.

Universal Protective Factors

Streissguth's secondary disabilities study (1997) also examined risk and protective factors associated with secondary disabilities. The researchers found 8 universal protective factors associated with lower rates of secondary disabilities:

1. Living in a stable and nurturing home of good quality
2. Not having frequent changes of household
3. Not being a victim of violence
4. Having received developmental disabilities services
5. Having been diagnosed before age 6
6. Having a diagnosis of FAS rather than ARND/pFAS
7. Having a low adaptive behavior scale score
8. Having an I.Q. score below 70.

The risk factors associated with higher secondary disabilities are the flip side of these universal protective factors. Unfortunately, youth in care with FASD often have not had these protective factors throughout their lives and are more likely to be plagued with the risk factors. This study allows us to see what interventions could be targeted at an earlier stage for individuals with FASD in order to facilitate better lifetime outcomes.

The Literature on FASD

While exploring the literature regarding my specific topic, I searched through the medical and the humanities fields. The focus in the medical field regarding prenatal alcohol exposure is on the clinical aspects of the disability including experimental research on animals studying the effects of alcohol on the fetus, diagnostic information, and research on small children. While this research has been critical to our understanding of the effects of alcohol on the fetus, the current project is more interested in the experiences and perspectives of individuals with FASD. Searches of several databases in the humanities fields also revealed little research from the perspective/experiences of those with FASD. Literature directly from the FASD community across Canada and the US, was used in this study including books, theses and articles. While talking about FASD, I think it is necessary to discuss the ‘politics of FASD’, issues related to gender, race and class, that tend to be ‘shoved under the rug’ in our discourse about this disability.

Much of the literature on FASD can be characterized as pathology oriented that is, focusing on the deficits and inabilities of individuals with FASD, with limited consideration to their perspectives and experiences (Copeland, 2001). There is often shame, blame and stigma attached to FASD. There remains a common perspective in mainstream society that FASD is a result of individual pathology (alcoholic mother) and that prenatal alcohol use is an intentional act of abuse towards a child. Substance use during pregnancy has been equated with child abuse and these so called ‘bad mothers’ are considered at best ‘sick’ and at worst ‘criminal’ (Rutman, D., Field, B., Jackson, S., Lundquist, A., & Callahan, M., 2005). Prosecution of women for their behavior during

pregnancy has targeted women of color and lower socioeconomic status (Rutman, et al., 2005). In “Florida, South Carolina and in several other states, pregnant women can also be jailed for, purportedly to ‘protect the fetus from damage’ if the mother has acknowledged drug use” (Whiteford & Vitucci, 1997). There is often no analysis of the historical, familial, societal and psychosocial issues surrounding why a woman might drink during pregnancy. Boyd (1999) and Ferguson (1997) have also challenged this notion of mother blaming and talk about sexism and racism operating in the diagnosis and talk about FASD. Malbin (1993b) through her own personal story discloses her experience with the stigma and stereotypes associated with drinking during pregnancy. She provides her own story as a case example of the experience of living with having used alcohol during pregnancy and figuring out years later that her daughter had FAE.

Along the same political lines as the issue of mother/women blaming is the false belief that FASD is associated with cultural and socio-economic background. FASD is universal and affects all cultures and communities where alcohol is being used. However, FAS is popularly understood in North America to be a ‘First Nations problem’ (LaBerge, 2000). Why some people get diagnosed with FAS and others don’t has less to do with ethanol teratogenesis and more to do with marginalizing social relations (LaBerge, 2000). Jones (2003) reported that Aboriginal children in Manitoba are six times more likely to be referred for an FASD assessment than are non-Aboriginal children. In our province, there is a high representation of FASD in the Aboriginal population, especially in the more Northern communities where isolation, poverty, and third world conditions exist. Tait (2003) argues that intergenerational links between residential schools, particularly with regard to sexual and physical abuse experienced by

children who attended the schools, mass adoption of Aboriginal children in the 1960's and 70's, and the introduction of alcohol by Europeans into Aboriginal communities, have collectively contributed to high rates of FAS and other related illnesses among Aboriginal peoples. This analysis of the cause for the over-representation is not well reported nor talked about in the larger community due to the stigma and sensitivities around the issue.

Anecdotal evidence suggests that the rate of FASD among the dominant culture (especially those in the upper echelons) is higher than reported and those individuals might be diagnosed with more 'acceptable' and less stigmatizing diagnoses, for example, Autism or ADHD. LaBerge (2000) reminds us that people are diagnosed with FAS because they have problems-in-living deemed associated with ethanol teratogenesis. People without particular forms of problematic social relations generally do not receive a diagnosis. For example, white people diagnosed with FAS tend to be either poor or living within the care of an adoptive or foster family (LaBerge, 2000). The purpose of noting the discourse on the politics of FASD is to inform the reader of some of the hidden discussions and realities in the field. In exploring FASD through a political lens, one can see that there is a lot more to the discussions surrounding the disability than mainstream discourse admits.

The Experiences of Adolescents with FASD in Care

A journey through the literature found that there is no prior research regarding this specific topic, except for the research done by the Child and Youth Officer of BC (2006). According to Lynda Manser, Executive Director of the National Youth in Care

Network (NYICN) there are no publications produced by the NYICN specifically by or about youth with FASD in care in this country (Manser, personal communication, 2006). My guess is that without knowing it, due to the invisibility of the disability, some of the research by the YICN's across the country has in fact, included youth with FASD considering there is a large percentage of these invisible children in care. The NYICN that was created and extended across Canada in 1985 has allowed for the voices of many youth in care to be heard through several different types of avenues, although not formally including those children who are alcohol affected. This thesis project hopefully provides an eye-opening glimpse into the experiences of this unique group of kids in care.

Although the voices of youth with FASD in care have not been heard other than one known study, some important research has been conducted regarding children with FASD in care from the perspective of the caregiver (Brown & Bednar, 2003; Frankel et al, 2006; Gammon, 2000; Jones, 2003; McCreight, 1997; Normand & Rutman, 1996; Opie, 2003; Rutman & Copeland, 1996). Caregivers and service providers have time and time again reported the need for education for themselves (and family members) about FASD, as well as the skills to provide care that matches the child's particular needs. A higher level of collaboration between systems, specialized supports for families, and timely and supportive responses from practitioners are needed. When resources are not readily available and caregivers have no support, the challenges that come with the disability, i.e. behavioral problems, limit the caregiver's ability to manage the behaviors, which often leads to placement breakdowns. Youth with FASD experience multiple placements through their time in care, which are linked to long term emotional problems,

behavioral disorders and learning problems (Jones, 2003). Transitions to independent living, parenting and working with human service professionals during the transition to adulthood are further challenges that require special consideration (Rutman & Copeland, 1996; Fuchs et al, 2005; Child & Youth Officer for BC, 2006).

Prevalence Rates- FASD in the General Population

Overall, it is estimated that FASD affects up to 9.1 of every 1000 babies born in the United States and Canada (Koren, Nulman, Chudley, & Locke, 2003). Health Canada estimates that 1 in 100 in Canada could be diagnosed on the FASD spectrum. Canadian population studies suggest that the incidence of FASD can be as much as 33% or higher in poor, disadvantaged communities (Chudley, 1991). In addition, the incidence of FASD in some First Nations communities has been found to be higher than in the general population (Burd & Moffat, 1994; May, 1991).

Prevalence Rates of Children in Care with FASD in Manitoba

According to Barth (2001), an estimated 80% of teens with FASD in the U.S., are in the care of child welfare agencies and Jones (personal communication, 2003) has offered that the number is similar for adolescents with FASD in Manitoba. A 2005 study on children in care with disabilities in Manitoba revealed that 33% of children in care have a disability, most having multiple disabilities (Fuchs, Burnside, Marchenski & Mudry, 2005). Half of these 33% have or are suspected of having FASD. The overwhelming majority of children with FASD (89%) were in permanent care of an agency. These children are also known as “permanent wards”, within the child welfare

system. The culture of origin of children in care with FASD was also looked at. The researchers found that 81% had Treaty Status, 8% were Métis, 5% were non-Aboriginal, 4% were non-Status and 1% was unknown culture of origin. Regarding involvement with their families, 47% of children with FASD in care had no contact with their parents. Additionally, it was found that 46% of children diagnosed with FASD, had co-occurring mental health disorders, the most common being ADHD (39%). Finally, the gender difference was parallel to that of FASD in the general population, approximately 60% males and 40 % females had FASD.

In summary, half of children with disabilities in our system have or are suspected of having FASD. These are considered to be conservative estimates. Almost 9/10 of these children are permanent wards, which means that there are no plans for them to return to their families and the system will “care” for them until age of majority. Half of these children with FASD have no contact with their parents stripping them away from their family, culture and community. An alarming 93% of these children were of Aboriginal descent. Co-occurring mental health disorders were present in almost half of the children with the most common dual diagnosis being Attention Deficit Hyperactivity Disorder (Fuchs, et al, 2005).

An additional piece of the research on children with disabilities that is significant for the reader to note is the incidence of maltreatment towards children with disabilities. Children with disabilities suffer maltreatment at three times the rate of children without disabilities (Sullivan & Knutson, 2000) and those with accompanying behavioral disorders face the greatest risk at seven times the rate of children without disabilities. This leaves our children and youth with FASD at high risk for maltreatment, especially at

the most challenging time of adolescence. Giunta and Streissguth (1988) report individuals with prenatal exposure to alcohol are at higher risk than average for physical abuse, sexual abuse and neglect.

Part 2: Youth in Care and their Experience

You came, you became a number, you ate, you slept. They kept your mind under lock and key. They chained you to rules, to their way of life. You went, they waved, they soon forgot. But did you?

Poem- "They soon forget" by an anonymous youth in care 1987

The term "youth in care" refers to youth who are in some form of government care including the child welfare and protection systems, children's mental health systems, and youth justice systems (Manser, 2004). In Canada, there are over 80,000 children and youth in care in the child welfare system and an additional 25,000 in detention centers and youth justice facilities with countless more in mental health facilities (Manser, 2004). The state assumes legal guardianship of children in need in place of the parent and the children are then designated 'in care'. Youth in care come from a variety of different backgrounds and experiences including neglect, family violence, struggles with addictions in the family, physical/sexual/emotional abuse, multiple traumas, family involvement with the law and other experiences. The result is often a child who has physically survived these events but has learned that the world is unpredictable, untrustworthy and unsafe and their emotional, social, psychological, intellectual and spiritual development has been harmed. They are uprooted and thrown into care with strangers with their life baggage, expected to behave and get on with their daily routines.

The two most common reasons for children with disabilities in Manitoba, having to come into care are Conduct of Parent and Conditions of Parent (Fuchs, et al, 2005). Both include the parent's inability to care for the child for a number of different reasons either due to their conduct (e.g. drinking and not supervising) or conditions (e.g. mental health issues). Only 6% of children come into care because of their behavior and the parent's inability to continue caring for them. Therefore, most of the time, they are being forced into care because of something that they were not responsible for.

Youth in care tend to come from marginalized, disadvantaged families with low income and education. In Manitoba, an alarming 70% of our children in care and 96% of children in care with FASD are of First Nations, Métis and Inuit culture of origin (Fuchs et al., 2005). Considering that Aboriginal people account for 13.6% of Manitoba's population (Service Canada, 2006) and fewer than 5% of children in Canada are Aboriginal (Human Resources Development/Statistics Canada 1996), this is a staggering number of Aboriginal children in care. The over-representation of Aboriginal children in care is linked to the inter-generational effects of the historical factors of colonization, the residential school system experience and the subsequent "scoop" of Aboriginal children from their families by the Children's Aid Society (CAS) in the 1960's. More Aboriginal children are placed in out-of-home care today than in residential schools at the height of the residential school movement (Blackstock, 2003). The high representation of Aboriginal children is also seen in the youth justice system in Manitoba, with approximately 80% of the youth in the Manitoba Youth Center (MYC) being of Aboriginal descent (La Pierre, personal communication, 2005). This horrific reality for Aboriginal people needs to be addressed and solutions explored.

Adolescents in care are not generally asked about their experience, nor are children's voices heard in society in general. During my search about children and adolescents' experience, voices or perspectives, I found a limited amount of literature from children's perspectives (Carroll, 2002; Davis, 1998; Gilligan, 2000; Lewis & Porter, 2004; McLaughlin, 2005; Sanders & Munford, 2005). Gilligan (2000) writes about the importance of listening to the child in foster care. The words of the young people bring to life their lived experience and illuminate for the adults in their lives, the tensions, dilemmas and pain that is often their lot. Gilligan warns that if adult caregivers and social services are to have any hope of meeting the needs of children in foster care, then they must listen very closely to the lived experience of children in foster care. McLaughlin (2005) explores some of the methodological challenges with working with young co-researchers, as well as the ethical and practical considerations. Meaningful involvement of young co-researchers requires careful thought and consideration, but potentially offers a set of identifiable benefits including distinctive insights, access to 'insider' language and an authenticity in analysis not always available to more traditional forms of research (McLaughlin, 2005). It is increasingly accepted that children are co-constructors of meaning and do have a valid perspective worthy of inclusion in research, even at very early developmental stages and despite apparent disabilities (Greig, Taylor, & McKay, 2007).

The National Youth in Care Network (NYICN) has been outspoken about the experiences and needs of youth in care in this country. The members of youth in care networks across the nation that are run by current and former youth in care share a sense of powerlessness in the system and seek to empower youth to find themselves and regain

control over their lives, through support, skill building and healing opportunities (Manser, 2004). They also exist to voice the concerns and opinions of youth in care and attempt to improve the services for this group of youth. The NYICN has conducted research, produced many publications, worked on policy issues, advised child welfare professionals, and supported the development of over 70 provincial and community level youth in care networks across Canada (Manser, 2004). Many important and poignant stories come out of the NYICN literature regarding the experiences of youth in care.

Voices- Manitoba's youth in care network (MYICN), created a guide about living in care called "Moving in, moving on and moving out" (MYICN, 2000) for youth in care to help them through the journey of being in care. The handbook gives the youth pertinent information regarding coming into care, their rights as a youth in care, issues being in care, and moving out into independence. *Voices* has produced publications as well including their quarterly newsletter, they have a radio show broadcast from the University of Winnipeg and a website on the internet. This resource is available to youth in care in this province, whether they are aware of the resource is another story.

There are two noteworthy research contributions in the field of youth in care that relate to the current study. Dame (2001) writes about the unexplored area of the experiences of Queer youth in care in order to develop a better understanding of the issues related to these youth and the need for specialized services due to the uniqueness of their experiences and needs. Callahan et al. (2005) asked young moms about their experience in care, asked social workers about how they perceive their practice with young moms in care and their children and finally, what policies and practices are most essential to shaping these young people's lives and how might they be strengthened or

changed. Both studies are relevant to the current research in that they mirror similar dilemmas for youth with FASD in care due to their unique experience, different needs and the requirement for specialized service in child welfare. Also, recommendations for best practice regarding the specific group of youth in care are discussed and both studies talk about the challenges of lack of resources, specialized and supportive services to Queer youth and young mom's in care. Treating all youth in care the same and providing standardized services, not recognizing the need for differential interventions, contributes to the cycles of deterioration for each of these special groups of youth in care.

In this and other research concerning youth in care, inevitably we end our research by noting the lack of post-care resources and assistance once a child reaches the age of majority ('the cut off'), which is a huge issue for all youth in care. The more marginalized the youth in care (due to race, sexual orientation, multiple traumas and abuses, cognitive disability, gender, etc.), the more challenging the cut off and the more at risk the individual is in the community. The concerns about youth moving out of care transitioning to adulthood have been a focus for those advocating for change in the lives of youth in care (Cazabon, 2005; Fuchs, 2006; Lambe, 2006; Manser, 2004; Raychaba, 1988; Rutman et al., 2007, 2009; Twedde, 2006). Youth in care who turn 18 and are ejected from their *homes* in the child welfare system, are alone without the skills to live successfully and often end up struggling with addictions, homelessness, mental health difficulties, unemployment, early parenting, and incarceration. However, many end their time in care in an institutional placement which provides even less opportunities for informal supports after the youth reaches the age of majority (Jones, personal communication, 2010). This contributes to the cycle of intergenerational children in care.

While in care, children with FASD usually receive an adequate level of care with at least their basic needs being met. However, when they turn 18, they are expected to fend for themselves with very few community resources available to advocate effectively on their behalf (Schibler & Newton, 2006). An extension in care (continued service from Child and Family Services after age 18) might happen for those youth who will be transitioning to adult community living due to having an IQ under 70, or those that are regularly attending school but often young adults with FASD do not fall into these two groups. As a result, they are often on their own with no support and resources and eventually end up in the care of the adult systems of justice or mental health.

Part 3: The Voices and Experiences of Youth and Young Adults with FASD

The literature regarding the perspectives and experiences of youth and young adults with FASD has grown in recent years, especially in western Canada. There are several contributions to the knowledge and experience of adolescents and young adults with FASD. Kleinfeld & Wescott (1993, 2000) compiled stories from adolescents and their caregivers related to a myriad of factors related to living with FASD. The stories parallel the authors experience with her son Antone. Berg et al., (1997a & 1997b); Stetina, 2003; Schwab and Kydd, 2007; Cook and Prouxl, 2003) created books in comic and story form for children living with FASD some of which include the words of young people with FASD. Malbin (2001) & Buxton (2004) write about their experiences as birth/adoptive mothers of children with FASD, how they came to the realization that drinking was the cause of their children's disability and dealing with the feelings attached

to this realization and the challenges ahead with living with FASD. The stories and words of individuals with FASD are included in these works. Mayer (1999) compiled several stories and articles in this book which have the voices and experiences of young people with FASD expressing what it is like to live with the disability.

Many authors have included individuals with FASD in the creation of these works and have tried to facilitate having their voices heard in an attempt to have the reader better understand their experiences. The limitations and challenges that individuals face, as well as their ability to find strengths in themselves have been illustrated. In the research by Rutman and Copeland (1996), regarding the experiences, needs and support strategies of young adults with FAS/E their research participants are not formally identified as youth in care with FASD, but some participants speak about their experiences with social workers and youth care workers. In this research, young people with FASD had their voices heard regarding their experiences of learning, transitions to independent living, pregnancy and parenting and interactions with human services. They contributed their perspectives to the recommendations for support strategies. Copeland (2001) explored the experiences and meanings of friendship of young people with FASD, which included hearing young peoples' stories.

The literature that focuses on the voices and experiences of young people with FASD is a powerful and critical contribution to understanding their needs. The wisdom of those living with FASD should lead the way to implementing changes in the child welfare, justice, mental health and education systems and helping mainstream society see that individuals with FASD have a voice and they can lead successful lives with appropriate support.

Conclusion

There is limited research on the experiences of individuals with FASD in general and especially the voices of adolescents with FASD in care. This study contributes to research in the field of FASD and child welfare to begin to fill this significant gap. As expressed earlier, an anti-oppressive research approach involving youth with FASD in care has not been taken up and consequently, provides a unique contribution to the existing literature. In the recent past, child welfare has begun to look at our children in care with FASD in this province and realize that the service provided to them is inadequate and not in line with best social work practices. According to Fuchs, et al. (2005), “The child welfare system is not currently structured in a manner to serve children with disabilities and their families. The data indicates that many children with disabilities and their families are not receiving, from the child welfare system or from other service sectors, the services necessary to meet their needs”. These concerns not only relate to our province but are found globally and therefore, a global FASD initiative is needed. This group of youth in care requires specialized services while in care, extensions in care and maintenance at age 18 and a proper and supportive transition to the adult services community after age 21. FASD is a life-long disability and requires supports be available throughout the life span. What is needed is a global paradigm shift (Malbin, 1993b) regarding FASD and the importance of making it a policy and practice priority in the fields in which FASD is a factor. We need to ask individuals with FASD about their experiences and needs and refer to the experts for some solutions.

Chapter 3

Methodology

Introduction

This chapter explains the details of this research project. First, I describe the methodology and the theoretical framework. I outline the particulars of the research process, from data collection and analysis to ethical issues. Finally, I explore the limitations and strengths of this research through my examination of the needs and experiences of young people with FASD in care.

Methodology

This qualitative study attempted to address some of the gaps in the literature regarding the experiences and needs of adolescents with an FASD in care. Through personal interviews with several young people, the aim was to hear the voices of this group of youth and learn about their experiences in order to facilitate better understanding and support for these adolescents. The most fitting methodology to bring forth this information is qualitative research, which provides thick and rich descriptions with significant meaning (Merriam, 2002). According to Creswell (1998),

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting.

Denzin and Lincoln (1994) state “qualitative researchers underscore the value-laden nature of inquiry”. Qualitative researchers highlight socially constructed reality, the intimate relationship between researcher and what is studied, and what shapes the

inquiry. They question how social experience is created and given meaning, and seek to show these processes. Creswell (1998) reminds us that we “employ a qualitative approach to emphasize the researcher’s role as an *active learner* who can tell the story from the participants’ point of view rather than as an ‘expert’ who passes judgment on participants” (p. 18). Many qualitative researchers acknowledge their worldview, values and beliefs through their work. This project marks my first attempt at anti-oppressive social work research, a unique method of doing research which promotes social justice and the collective construction of knowledge between researcher and participant.

Theoretical Framework: Anti-Oppressive Research

It has taken many years to find a comfortable place in research. I could never understand why a researcher would only ever want to count the number of people who experienced something without asking what exactly the experience or phenomena was like for the person. I have asked myself, “What makes the researcher any better than the subjects”? Why is the researcher considered the “expert” if “he” has not walked in the ‘subjects’ shoes? And “how can ‘he’ not have any opinions or feelings about the topic being studied?”

When I was introduced to anti-oppressive research a couple of years ago in my qualitative research course, the “light went on” and my interest in *research* was piqued. To hear that I have already done *research* and that we do *research* on a daily basis without even knowing it was a comforting revelation. Over the years as a social worker, I have sought social justice for many marginalized, voiceless ‘clients’ that I have been blessed to meet and entrusted to work with. Those feelings have intensified over the

years and have impacted on my practice as a social worker and as a student researcher. My feminist, youth-centered worldview, my personal and professional values and ethics, mesh well with an anti-oppressive research approach.

Being an anti-oppressive researcher means committing to social change and taking an active role in that change, that there is a political purpose and action to your research work (Potts & Brown, 2005). Since I began working on my thesis, I have felt the need to produce something at the end or do something more than “just complete”. I work every day as a clinical social worker to promote social justice and self-determination of youth and families. I hope to someday put some of the recommendations into action after the research in some form.

Potts and Brown (2005) outline three tenets of anti-oppressive research (A O R): anti-oppressive research is social justice and resistance in process and outcome. By this they mean that some research attempts to have the goal of social change, but the process or the journey has maintained the status quo/positivist/oppressive worldview. A O R seeks to be anti-oppressive through the journey and in the results. Secondly, A O R recognizes that all knowledge is socially constructed and political. In traditional research, the “truth” is sought. In A O R, the belief is that truth is created, “human-made” and laced with biases, privileges and power differentials. In A O R, we are looking for meaning and understanding in order to facilitate change. Due to the admission of these facts and the belief that research can be a form of resistance, AOR acknowledges that all knowledge is political. Thirdly, the anti-oppressive research process is all about power and relationships. This process constantly attends to issues of power and shifts power to those with the lived experience under study as much as possible.

Assessing the Best Methodological fit

While an AOR perspective/worldview was obvious for me to implement into this work, the research design was a challenge. When researching with an oppressed population such as adolescents with cognitive disabilities, the researcher needs to take care in the decisions regarding her methodology. Ideally, I wanted to include the participants as co-researchers throughout the process of the research and have them included in several different activities from data collection to the analysis, recommendations and post-thesis activities. This had to be modified during the ethics process as I realized that I was naïve to the complexities around the amount of time, energy and possibly stress to participants would be endured with too many steps and expectations asked of them. I decided to keep it simple and ask each participant for a personal interview only. The recommendations for professionals and care givers were formulated by extracting the participants' suggestions and recommendations within their interviews.

Another challenge in the process of locating the best methodological fit for this research was assessing different types of methodologies. Phenomenology, narrative research, grounded theory and participatory action research were all researched and assessed by myself and my advisor over time as to their appropriateness and fit with the research vision. These methodologies, while they have many desirable properties either required abstract reasoning in the analysis which may have been difficult for the participants or they were deemed beyond the scope of this project. Thematic analysis was chosen as it provided a concrete and straightforward format for analysis that was

seen as akin to the way that individuals with FASD process information. After careful consideration of cognitive capacity, the number of activities expected of participants and also the time constraints of this small scale research, as stated earlier, I decided to scale down the participants involvement. Thematic analysis was kept as the mode of analysis although the participants were no longer involved in analyzing the data. In contrast to other methods, thematic analysis is not wedded to any pre-existing theoretical framework, and therefore it can be used within different theoretical frameworks and can be used to do different things within them (Braun & Clark, 2006). After careful assessment regarding methodology, an anti-oppressive research philosophy was used with the method of personal interviews for data collection and thematic analysis was undertaken by the researcher resulting in co-created recommendations for the child welfare, justice, mental health and education systems.

Research Methodologies with FASD Populations

Some of the methodologies used when studying adolescents and young adults with FASD have seemingly been a good fit. Deborah Rutman has contributed to the research on the experiences, needs and support issues for young adults with FASD in a significant way (Rutman & Copeland, 1996; Rutman, LaBerge & Wheway, 2002, 2005). Participants were interviewed about their personal experiences of having FASD, their support issues and needs. Her research used the principals of grounded theory and narrative psychology for the analysis. Themes were extracted from the stories and placed together into a coherent organization. This methodology was successful for her in extracting information in a natural way from individuals with FASD. Similarly, the

FAS/E Support Network of B.C. has also used narrative or storytelling methods of information gathering that have proven successful in the eyes of researchers and also the individuals themselves. Copeland (2001) used a narrative technique and secondary analysis of the data in her friendship study with young adults with FASD, which provided rich, thick descriptions. The study also birthed many important findings about the individual's experiences of friendship and the meanings of friendship. Helpful recommendations have come out of the study about how to better support and teach youth with FASD and social situations and making friends from a younger age. Getty (2000) offered a mixture of qualitative and quantitative methods in her study on factors of stress related to the perceptions and attitudes of children and families affected by FAS. She used an ethnographic approach within her qualitative methodology and triangulated with quantitative data obtained from the Parenting Stress Index. The strength of this study is in the variation of information collected and the meaning that each had. She interviewed parents as well as children, which provides a well-rounded approach to the research.

In Rutman, D., Hubberstey, C., Barlow, A., & Brown, E. (2001), participatory action research (PAR) was used as the methodology with co-researchers from youth in care to explore their experiences with transitioning into adulthood. The researchers recognized that many youth in care come from marginalized and poor families, and live with disability and the consequences of trauma. The researchers struggled with issues such as power and responsibility in the relationships, the naivety of the researchers regarding the youths' life circumstances and their ability to be available to the research, and shared decision making was challenging as it was highly time consuming. Strengths of the research were that the youth did receive a decent wage, the co-researchers created a

series of life skills workshops and a guide and they gained computer skills. The co-researchers appreciated that they assumed the role of experts rather than clients.

Although the researchers feel that they failed to meet their social justice goals, as the co-researchers found that they were in the same position after the research, they still felt that PAR was worth conducting and that the benefits outweighed the costs.

Most of the research from the perspective of individuals with FASD has utilized a narrative or storytelling method with empowerment approach that has proven successful in the eyes of the researchers as well as the participants. This anti-oppressive approach to research has not been utilized in the literature that pertains to the experiences and perspectives of adolescents with FASD and is in this way, unique.

Why this Research is Important

Qualitative research in the area of the experiences of young people with FASD in care is imperative. As demonstrated in the literature review, conservative estimates of the number of children in care with FASD are substantial and the child welfare system admits that the current system is not set up to meet their needs. If we do not hear from those who live the experience and learn from this, we will continue to assume we have the answers for policy and practice changes and may continue to provide inadequate supports and services to this special population. Further to listening to the voices of these experts, we need to implement some of their ideas and formulate them into recommendations for the myriad of systems that work with people with FASD. We can take from this research that young people with FASD *do* have something to say about

their experience and have opinions regarding social change. They just need to be asked.

Research Design: My Role as Researcher

Anti-oppressive research recognizes the researcher as part of the research process and that it is important to address the researcher's biases due to their location. Decisions and choices that were made in the research were impacted by my social location. It was important to be reflexive in the process, continually analyzing decisions and changes and the reasons why they occurred. I conducted the research as a female, middle class, Caucasian, heterosexual, able-bodied, cognitively intact, graduate student, social worker and mother. I was an outsider looking in. I likely interviewed youth who have several levels of marginalization which compound their location. I also hold dual role status in that I am a Child and Family Services social worker, which was disclosed to the participants. I was conscious of the privilege that I held and the power differential in the relationship, made attempts to be as anti-oppressive as possible and documented my reflections on power and relationships.

In all AOR research, engagement and management of the research relationship needs to be considered and dealt with in the best interest of the participants. When we look at power and relationships in this type of research, we seek as much as possible to balance the power differential and to build collaborative relationships. The participants are the experts, as they are the ones who have lived the experience or are "those with epistemic privilege" (Potts & Brown, 2005, p. 263). The participant's control over much of the process and the co-creation of knowledge between researcher and participants is what sets anti-oppressive research apart from other approaches.

Data Collection Methods

Personal Interview

Personal interviews allow those who have been traditionally silenced and not had the opportunity to tell their own stories, to do so (Esterberg, 2002). Children and youth, especially those in the care of child welfare, tend to have their voices silenced by the adults in charge of them. The notion of children being seen and not heard seems to still be a widely held belief in society. Young people in care struggle with feeling powerless to change their lives. The system has ultimate control and the youth do not have many choices. In 1985, the National Youth in Care Network (NYICN) was formed by a group of youth in care from across Canada. They shared a feeling of powerlessness- they felt strongly that the child welfare system had taken away from them control over their lives (Manser, 2004). The purpose of the NYICN is to help youth in care find their voices and regain control over their lives through support, skill building and healing opportunities. This research serves to honor those youth in care networks across the nation who have been instrumental in creating social change and empowerment for youth in care.

The data was collected through individual interviews with each of the participants. An interview guide was used (see Appendix H- Interview Guide) as well as participant observation and some open conversation. I conducted five interviews for the purposes of this thesis project. I recorded each interview on a digital recorder except one, as one participant was uncomfortable with the recorder and preferred that I take notes. I transcribed the data from each interview on my own and listened to the recordings several times to get a feel for what participants anguished over the most and to ensure accuracy of the transcription. The data was safely stored in a locked filing cabinet in a locked

room before transcription took place and the recordings were erased after the data was transcribed.

Before each interview, the consent form (see Appendix E-G- Consent Forms) was read to the participant slowly paragraph by paragraph with an advocate present. On one occasion, the participant read the form aloud. After each paragraph, the participant was asked if they understood what was just read to them. If not, it was re-read or explained in a different way to ensure comprehension. Each participant was asked if they agreed to take part by their advocate and the advocate advised the researcher that they believed that the form was understood and the participant wanted to participate. All parties signed/provided verbal consent to participate and a copy was provided to them for their records after the interview. Each participant was asked to provide a code name to be used in the final thesis. Each participant enjoyed this as they chose names they wish they had or thought were “cool”. It was explained that the purpose was to provide anonymity and the word anonymity was explained in concrete terms. The interview questions included the participant’s history in care, experiences living with FASD, support needs and recommendations for professionals.

After each interview, I reflected on the process and made notes in my journal for my audit trail as a method of ensuring the trustworthiness of the research. The interviews ranged from 27 minutes to one hour and fifteen minutes in length. I tried my best to conduct an FASD-friendly interview. For example, keeping language to a minimum, asking one question at a time and slowly, allowing time for information processing of the question, clarifying and at times making things more concrete in order to facilitate a reply, and noticing when a break was needed. I noticed during the replaying of the

interviews that I often did not allow enough time for processing information, at times I used too much language to try and help the participant understand the question, and realized later that some of the questions were too abstract and/or complex. Each interview became more FASD-friendly as I learned from my mistakes. All the participants answered all of the questions and completed the interviews.

The location of the interview was in a familiar place to the participant and of their choice. Four out of five of the locations were in a sensory-friendly environment conducive to concentrating and maintaining confidentiality. However, one participant chose his foster home where there ended up being too much traffic (other youth) and distraction, which may have affected this participant's interview. The length of the interview, complexities and nature of some of the questions proved to be a challenge for some participants at times. Waiting, moving on to another question or saying the question in a different way helped with this challenge. Although youth had the option of doodling or whatever else might have been helpful for concentration, none utilized any external help with this. One participant rocked in his rocking chair, which he said helped him to stay calm and concentrate. Another participant asked to sit in a certain seat facing the door where he would be most comfortable. None of the participants took a break from the interview although it was offered to each of them. All but one of the participants had a staff member with them during the interview who assisted with missing information or when participants had trouble remembering something. At the end of each interview, participants were paid \$20.00 and thanked for sharing their story. The money was given to them with their advocate present. Also, each participant was transitioned to

a care giver after the interview and the care giver was asked to check in with them about how they were feeling and intervene accordingly.

Recruitment and Profiles of Participants

The participants were selected purposefully based on their ability to provide needed information. The necessary criteria to participate in this research was for the participant and/or care giver to identify the participant as an individual who was prenatally exposed to alcohol, having at some point in their lives resided in care, and being at a developmental level in which the interview process was viable. As stated earlier, five participants took part in this research. Originally, the age range was from age 16 to 26. I ended up extending the range to age 30, as I had someone interested who was 28 years old and was finding it a challenge to recruit participants.

Initially, I sought out professionals in the FASD community who I had worked with previously and thought they might have some clients that would be interested in the project. I initially called them and spoke to them about the research over the phone and then emailed the recruitment poster and email script of the research to them to look over and share with their clients. The professionals were employed by a myriad of agencies and community resources: Macdonald Youth Services- Specialized Individual Program (SIP), Clinic for Alcohol and Drug Exposed Children (CADEC), Child and Family Services (CFS), Fetal Alcohol Family Association of Manitoba (FAFAM), Interagency FASD Program, Manitoba Youth in Care Network (MYICN), Manitoba Youth Center (MYC), Life's Journey Inc., Provincial Special Needs Program, Manitoba Foster Family

Network (MFFN), Healthy Child MB, Mennonite Central Committee-FASD Program, and 4 CFS FASD Specialists. Most professionals returned my calls and responded well to the research. However, few were able to provide potential participants. I think there were a myriad of reasons for this. Most of the contacts said that they did not have any or were not in direct contact with clients that fit the criteria. Some said that they likely had clients that fit the criteria, except they are not aware that they have FASD and could not speak to living with the disability. Others advised that the research might bring up historical issues for their clients who already have a myriad of serious issues affecting them and they lead very high risk lives. In this light, they said they would not approach them and felt the need to protect them. Still others attempted to get permission from superiors in institutions, which led to time lags and too much red tape. Additionally, there were a few other similar FASD projects occurring at the time of my recruiting process with Métis CFS, Mennonite Central Committee, and U of M which I think affected my recruitment, as participants fitting the criteria are limited.

I was cognizant of the fact that due to my past work with youth with FASD, previous clients might respond with interest to this research. I felt strongly that if the relationship was already there and they had an interest in having their stories told, that they should be invited to participate in this project. This was explained in my Ethics Submission and I was granted the authorization to include previous clients as participants if they expressed interest. Two out of the five participants were previous clients of mine. The other three were recruited through a Child and Family Services social worker, a previous co-worker at MYS, and one of the contacts that I initially sought out. Only one of the adult participants called me herself to express interest, set up an interview time

with her staff and myself and participated in the interview, on her own. The other four interviews were organized through care givers/professionals and they were also present in the interview. All five participants signed the consent forms or assented to the research with an advocate/guardian present. As well, I insisted that all five have an advocate sign the consent form and also be present when I gave each participant the \$20.00 stipend due to the participant's vulnerability and my ethical obligations to ensure informed consent.

The study analyzed data collected from interviews with five young people ranging in age from 16 to 28. The only youth in the study, was a 16 year old male who was living in a foster home (extended family). He was attending grade 10 at a school nearby and was not working, although had in the past. One 18 year old female was extended in care with CFS living in an apartment with 112 hours of staffing per week through Macdonald Youth Services. She was not working or attending school at the time of the study, but wished to return to school and graduate grade 12. A 19 year old male was living in an apartment with 9 hours of staffing per day from Adult Services and also spent some weekends with his adoptive family. He was working part time at a restaurant on the weekends and attending school during the days of the week. A 20 year old female was living in an apartment with 22 hours of staffing per day with Adult Services. She was working casual in the office at her placement doing office work. The eldest of the group, was a 28 year old male who was living in an apartment with 12 hours of staffing per day from Adult Services. He was working 4 hours a day, four days a week doing maintenance and office work for a community organization. All five individuals had a significant amount of support and supervision, which probably contributed to making it possible for them to be in this study. Those with FASD who do not have appropriate

supports and services would be very hard to reach in order for them to participate in research.

All but one participant came into care as a baby or small child, moved to a foster/adoptive/extended family home and then came into care again as a teen or pre-teen until age of majority. The other participant came into care as a pre-teen after living with extended family most of her childhood because her birth mother could not parent her. Four out of five participants were of First Nations descent and one was Caucasian. Two were female and three were male. Three participants had a formal diagnosis under the FASD umbrella and two did not but identified as someone who had been prenatally exposed to alcohol.

Although the sample size was small, there was consistency of responses across interviews, which also matched a lot of what the literature tells us about the experiences of young people with FASD.

Informed Consent

For this research, interested parties were required to seek the consent of their guardian if they were a youth in care as well as those young adults that are in the care of Adult Services and considered vulnerable persons. Determination of a participant's ability to legally provide consent and the appropriateness of them taking part in the study was assessed by the guardian/advocate and the researcher, prior to the interviews in a conversation regarding the potential participant's cognitive capacity. As a social worker with specialization in this area and much experience working with individuals with FASD, I am particularly well-placed to assess who is capable of giving consent and who

is not when I have appropriate information about their needs, the services currently involved with the participant and in assessing the individual in person. All the guardians/advocates advised that each client was appropriate for and had the capacity to take part in the study.

One participant was a youth in care who received consent from Winnipeg Child and Family Services to take part in the study. One adult who was extended in care received permission from Child and Family Services. The other three adults, although they were under the care of Adult Services, did not have a Substitute Decision Maker (SDM) and therefore, could consent to research on their own. Three out of five of the participants had an I.Q. under 70 as they were entitled to and receiving Adult services. The other two had not been tested at the time of the study and therefore, their IQ's were unknown. I recommended that each participant have an advocate present, someone who knew them and their capacity to consent to research and asked that the advocate take part in the consent process. It was helpful for me as the researcher and the participant's appeared to feel supported with their staff/parent/therapist being present during the interview as well.

After noticing that there could be several scenarios at play in this research, it became necessary to create three separate consent forms. An Assent Form was created for those youth who were in care and could not legally consent to research and those that could not read the form themselves and therefore, provided their verbal consent. A Consent Form for Guardians was created for the guardian of those who could not consent themselves to sign as authorization for the person to participate. Finally, a Consent Form for Independent Adults with a space for an advocate to sign was created. The three

consent forms were formatted in a standard format due to the constraints of the ethics review process. I felt uncomfortable with the length of the document, too much information on the pages, and the abstract language used. I noticed several of the participants getting a bit agitated and they seemed to want the process to be over with and presented as frustrated. I broke the document down into smaller pieces and took pauses between sections to make this a bit easier. This was certainly considered a challenge in the process and did not feel like it was in line with anti-oppressive philosophy.

A more true anti-oppressive consent process would focus on the researcher's commitments and obligations to the participants and would allow for as much control over the process of the research as the participants chose. The commitment given in this research was that the participants would have the opportunity to have their story heard and would have the opportunity to have input in the creation of recommendations for best practice for youth with FASD in care.

Data Analysis

Meaning Making through Thematic Analysis

Qualitative thematic analysis was chosen as the most appropriate method for analyzing the data. Thematic analysis is a process for encoding qualitative information into themes. It exemplifies the goal of qualitative research, which aims to discover lived experiences and meanings that is, the insider's view of the lived world (Luborsky, 1994). Thematic analysis fits with this research as "it can be used in many traditions to process, analyze and/or interpret his or her information, regardless of her or his ontology or

epistemology” (Boyatzis, 1998, p. 6). It allows for a more comprehensive understanding of the phenomenon because the observations, findings, and interpretation of meaning are easily communicated to those who are using different methods (Boyatzis, 1998).

There are many different interpretations of thematic analysis and the style that was the best fit for this study was breaking the analysis down into six phases (Braun & Clarke, 2006). First, I listened to the interviews in an active way listening for patterns several times and transcribed the data on my own. I checked the transcriptions for accuracy by reading the transcription again while I listened to each interview. Transcription is seen as a key phase of data analysis within interpretive qualitative methodology. Following each interview, I listened to the recordings and made notes of patterns of experiences that were most often raised by participants. I recorded direct quotes and paraphrased common ideas. In addition to interviewing young people, I documented various aspects in a journal. This included my observations, conversations, reflections, feelings/ethical issues, new questions I had, and preliminary analyses. These were combined and included in the analysis and discussion sections of the thesis.

Phase two involved generating initial codes whereby I made an initial list of ideas about what was interesting in the data that might form themes across the data set. I made copies of the transcriptions and cut the narrative out of each set of comments and placed them in a pile. I then gathered and sorted the narratives based on similar responses. In Phase three searching for themes, I sorted the different codes into potential themes, including a miscellaneous pile. Phase four consisted of reviewing and refining themes and re-reading the entire data set. In Phase five, I defined and named each theme and analyzed the data within them. The themes were looked at and themes and sub-themes

were chosen in the refinement process. Themes and sub themes were given working titles. I returned to the themes and the names they were given in order to find the right title for each. Finally the sixth phase involved producing the write up when the set of fully worked out themes was completed. Three sub-themes fell under each theme and an introduction and conclusion of each theme introduced and concluded the analysis of the theme. Vivid examples or extracts were chosen that capture the essence of the point being emphasized in the analytic narrative that was then set in the context of the literature.

Evaluation of the Research

Qualitative researchers strive to create “good” research. Merriam (2002) challenges researchers to ask the question, “Do I feel sufficiently secure about the findings to construct social policy or legislation based on them?” In anti-oppressive research, the assessment of whether our research is credible, actionable and trustworthy is a theoretical, principled question as opposed to a technical concern (Potts & Brown, 2005). Assessing how we are doing and critically reflecting on how we are doing the research is a continuous process, not a task at the end of the research. The important factor in qualitative anti-oppressive research is whether the research principles were adhered to throughout the research.

This anti-oppressive research study was set up to promote credibility because I positioned the participants as experts of their lived experience, I extracted important information from these expert sources, always insisting that the voices of youth in care with FASD be heard and looking to them as the primary source in order to create

recommendations based on their views. Anti-oppressive researchers ask, “Does the analysis ‘ring true’ to participants”? (Potts & Brown, 2005, p. 277) Continuously critically reflecting on the process and whether the tenets of anti-oppressive research are being adhered to also assures credibility. Another method that was utilized for the first part of the creation of this thesis regarding credibility is a “peer review”, which is a peer examination of the data related to the findings (Merriam, 2002). This peer review consisted of my thesis group which included 2-3 other students and my advisor and was utilized for part of the study. When the group dismantled, I used other professionals in the FASD community and my advisor as peer reviewers.

An anti-oppressive researcher asks whether they have been honest about their own biases and limitations and whether they have paid continuous attention to the issues of power and decision making in the process. An audit trail was used including journaling about my reflections, feelings and thoughts about the research, data, analysis, power and relationships from conception to conclusion.

In anti-oppressive research we ask whether we only touched on the issue or whether we made attempts to critically understand the focus of the research (Potts & Brown, 2005). Does the research have the ability to move into action in the end? We ask ourselves, “Does this research matter?” “Are the youth in this research and their cohorts, better off because of the research?” This thesis project is set up to have the capacity to move into action. I intend to look at ways in which the research could be brought to the attention of the systems which impacted the participants after the research and degree is completed.

Providing rich, thick description is a major strategy to enable transferability, and involves providing enough description and information that readers will be able to determine how closely their situations match, and thus whether findings can be transferred (Merriam, 2002). The intention of this research is not to generalize the findings to all youth in care with FASD, but the belief is that the experiences of youth in this project echo those of similar groups of youth in care in similar regions. Providing thick, rich descriptions affords the researcher the opportunity to gain a deeper understanding of the experience, which is the hallmark of qualitative research.

Ethical and Political Considerations

The ethics and politics are a critical piece in anti-oppressive research. Whether the researcher owns and talks about ethics and politics in her/his work or not, they are embedded in all research. Ethical guidelines for research seek to minimize risks, burdens, and harms; to increase the benefits of research for individual participants; to ensure that the consent given by participants or their guardians is freely offered and informed by knowledge of what the participants are being asked to do; and to maintain participants' privacy and confidentiality (Leadbeater, 2006). An anti-oppressive researcher critically reflects on the ethics of research and continuously asks herself questions about the research. "Who is the research for?" "Who will benefit/suffer?" "Will it exploit unintentionally?" This research is definitely for current and former youth in care, especially those who are alcohol affected. It was intended to benefit those youth in care who participated and had their voices heard as well as youth in care of the future.

These questions were continuously asked through the process of the research with the intention of having the participants' best interest at heart and to never risk exploiting them or creating any form of suffering for them. It was always a balance of assessing the importance of hearing the voices of this vulnerable and marginalized population and the ethics of recruiting them as participants, especially those that lead high risk lives. In the end, I believe it was important to provide them with the opportunity to have their voices heard regarding their experiences in care.

Before beginning this research, I obtained ethical approval for research on human subjects by the Psychology/Sociology Research Ethics Board at the University of Manitoba. In order to protect the participants' anonymity, I kept the names of the participants separate from the data and used a coding system. The participants' full names were not listed on any documents. The participants were advised of the limits of confidentiality through the consent process. They were informed of my obligation to report child abuse or neglect to the appropriate authorities if such information comes up in the interview. This was also stated in the consent form that they read or was read to them and they and their advocate signed. No disclosures came from any of the interviews therefore, no reporting to child welfare authorities was necessary.

This study, due to the nature of the questions about being in care and having FASD, had potential to bring up some emotions and possible stress. This potentiality was included in the consent form as well and participants were told that they could stop the interview, take a break, debrief and return to the interview or they could quit the interview all together if this occurred. One participant presented as agitated and stressed after talking about being in care and about their family. Putting the participants' needs

and emotional well being before the research project, I asked her if she was ok and wished to continue. She did not wish to take a break or quit but preferred to move onto the next question. At the end of this interview, the advocate was asked to check in with the participant to make sure she was doing ok. The participant was offered a list of resources, but declined the offer. All participants were transitioned to their care giver or advocate after the interview to ensure that they had support afterwards in case any delayed feelings came up for them.

The participants were advised that their participation in the study was voluntary and they had the right to withdraw their participation at any time. They were asked their permission for the researcher to use the digital recorder and one participant requested that it not be used and I took notes instead. The participants chose the interview location, they decided who was present during the interview and even the seat that they wished to sit in that was situated in the room they chose. Each person was advised that they could call me or email afterwards if they thought of something that they wanted to add that might not have come to them in the interview. They were provided with an opportunity to receive a copy of a summary of the research which all the participants agreed to.

Conclusions, New Questions, and Taking More Action

In anti-oppressive research, research is a circular, as opposed to a linear process. Although conclusions are captured at the end of the project, more often than not, there are more questions and wonderings than answers when all is said and done. Conclusions have a particular power because they are the construction of knowledge that leads to recommendations and actions (Potts & Brown, 2005). To ensure the co-creation of some

knowledge between researcher and participants, some of the recommendations were constructed directly from the narratives of participants.

Limitations and Strengths of This Study

As with any research, there were limitations in this study. In the hopes of doing the research as anti-oppressively as possible, I initially had a myriad of hopes for participants to be co-researchers and for them to take part in every aspect of the research to the point that it might become “their research”. Due to time constraints and concerns about their capacity to endure all the activities due to the challenges of the disability, the decision was made to have them partake in one activity. This felt to me to be your average qualitative research project and not the unique anti-oppressive study that I wanted it to be. But as I am reminded, this is a first attempt, a master’s level thesis and there are these real barriers that can occur in any study. As long as the principles of anti-oppressive research were adhered to, it is a good first attempt at this type of research.

Another limitation of the study was the way the consent forms were presented to participants. With their cognitive difficulties, the format and content of the standardized consent forms from the university were too abstract and lengthy for them. In the end, the consents were completed and an advocate was present to confirm comprehension. However, as I read the consent form to the participants, I could feel their frustration, their inability to not comprehend everything. I did not like the feeling of being a person who was creating this feeling for them when I actually designed this whole research for their benefit.

One of the participants chose his foster home as the location for the interview, which ended up being a high traffic environment with other teenage boys walking by and through. This, I believe influenced the interview. The participant was distracted and seemed to modify his answers to what would be heard as “cool” or acceptable for the other boys to hear. Some of his data was not used in the analysis due to this limitation.

Recruitment was a challenge due to the fact that this population of young people is vulnerable and often leads high risk lives. Care givers and professionals working with them felt the need to protect them from any further stress and therefore, kept them from being introduced to the research. Children in care are vulnerable on their own, let alone those with a disability. Recruitment took longer than six months to complete.

As in most qualitative research, the sample size was small and so the research does not claim to make a general statement about the experiences of all young people with FASD in care. However, checking back in the literature and in my own experience in working with young people with FASD, the findings are similar. If a very similar located group was studied in a similar geographical location, the data would likely result similarly.

Along with the limitations of this study there were also strengths. A significant strength of this study was the methodological framework used which provided a unique and empowering approach. As I noted in the literature review, research with young people with FASD is uncommon and using an anti-oppressive approach with this population has not been done before. Although there were several barriers to recruiting this group of young people and I had doubts about continuing this research, I plugged along and was able to find participants and gather the significant data that needed to be

heard. As well, participants were asked about recommendations for the systems and their words are included in the recommendation section of the thesis.

With providing a stipend to participants after the interview, I felt that this was a “fair trade”. I felt that participants some of which lead high risk lives experienced an example of a positive and pro-social way of sharing something of themselves and receiving something in return without any harm being done in the process. I would have felt as if I took something from them without having given something in return if I did not provide the stipend.

Having care givers involved in the process and in the actual interview was seen as a strength of the research because they helped the participant to feel more comfortable and provided accurate information when participants were unable to recall information or did not know how to respond. They also provided advocacy for the participant in that if in the future, the participant wanted to remember something from the interview, they could ask the care giver to be their “external brain”.

The timing of this research is a strength in that FASD has recently received appropriate attention in child welfare and there is now a recognition that FASD is a significant issue for this system and that there is a great need for intervention, research and changes to occur for children and families living with FASD. As well, researchers and management in child welfare authorities are seeing the benefit in including individuals with FASD in the process.

Another strength is that I took great care in each step of the process of this research to make sure that this would always be of benefit to those young people with FASD, that it would not be harmful or stressful, that it would be set up to be as anti-

oppressive and FASD-friendly as possible, and to ensure that their voices would be heard. This increased the credibility and trustworthiness of the research.

Lastly, sometimes young people with FASD are labeled and viewed as having no opinion, feelings, awareness and no goals and dreams in life. This research provides the reader with another perspective on the truth about people with FASD, that they are much more like “us” than unlike us and they do have opinions, feelings, awareness and have similar goals and dreams in life.

Chapter 4

Data Analysis (The Findings)

Introduction

In this chapter I present the findings of the study as they emerged from the interviews conducted with five participants and set them in the context of the literature by referring back to the literature to compare findings. Three major themes emerged from the data, namely: journey through care, circle of care and living with FASD. Within these major themes several sub-themes emerged, including: entry into care, placements, independence, family, caregivers, CFS, awareness and knowledge of FASD, secondary disabilities and strengths, achievements and dreams.

Journey through care refers to moving into care, placements and independence. *Circle of care* refer to relationships with people involved with the young person through their journey in care. *Living with FASD* encompasses the participants' awareness and knowledge of FASD and the impact on their lives including secondary disabilities and strengths, achievements and dreams. Many of the themes that emerged in the data analysis of this study mirror the findings within the existing literature. The findings set in the context of the research literature on youth with FASD in care provide the grounding for my recommendations, which will be the subject of the fourth chapter.

THEME ONE: JOURNEY THROUGH CARE

Journeys through care for young people are unique yet have common threads. In common with many youth with FASD, most of the participants had lived a significant portion of their lives in care. They entered into care as infants or small children due to their parent's inability to care for them due to their conduct or conditions. When they reached adolescence, most of the youth came into care again because of their behavior and being beyond the control of their caregiver. Some had experienced multiple placements while others had not. None of the participants were living independently due to their high need for supervision and support. Independence was considered a challenge for young people with FASD in most cases. Because this commonality amongst the participants featured extensively in their interviews, I have identified it as the first overarching theme. The sub themes coming out of young people's journey in care were: entry into care, placements and independence.

Entry into care

I knew from existing research (Fuchs, 2005) as well as my own experience working with Child and Family Services that alcohol affected children often are taken into care in the first days/months of life due to the parent's inability to care (Conduct of Parent). Besharov (1994) estimates 80% of alcohol affected children enter and grow up in the child welfare system before they are five years old. These issues are further compromised by multiple moves within the child welfare system and an increase in institutional type of placements as the child's needs increases (Jones, 2003).

Under the Child & Family Services Act (1985), Part 3, Section 17 (2) explains the circumstances involving a child in need of protection. Section 17 (2) (b) (ii) states that a child is in need of protection where the child is in the care, custody, control or charge of a person whose conduct endangers or might endanger the life, health or emotional well being of the child. It is not uncommon to see the young person with FASD come into care as a teen due to their own conduct (beyond the control of care giver). Under the Child & Family Services Act (1985), Section 17 (2) (d) states that a child is in need of protection where the child is beyond the control of a person who has care, custody, control or charge of the child. I was interested in asking about the timelines and the reason as to why participants came into care and their understanding of and feelings about this concept.

All of the participants spoke about their initial entry into care being when they were infants or toddlers as told to them by their care givers. The sense of journey is conveyed in these participants' stories:

I came into care as a baby. My biological mother gave me up obviously due to her drinking. And then I was put into foster care and then from there I was adopted by the foster family as a small child. I was in care for one year as a baby and then as a teenager. I left the adoptive family when I was 17 and I don't remember the reason. [Raymond- 28 years]

When I first came into care I started living in a hotel which was a temporary placement at about age 12. I lived there about a week and then I moved to a CFS shelter and I was there for about 8-10 months. Then I moved to a specialized placement and lived there for 5-6 years. After this, I moved into my own apartment with staff with the same specialized program. I did this for about a year till I was 18 and then Turning Leaf took over with Adult Services. [Sydney- 19 years]

When they were re-admitted into care as teens, two out of five of the participants spoke of coming into care due to their behavior after living with foster or adoptive families for most of their childhood and another participant reported that he could not remember the reason for re-entering care as a teen. Some of the participants understood this second time coming into care as being about their behavioral problems that were assumed to be beyond the caregiver's control.

*I was not in the best of moods all the time and I couldn't keep my cool and my Mom (adoptive) really couldn't help me. I had too much rage and she could not keep control of it so pretty much that is why I came into care.
[Sydney, 19 years]*

For some their journey in care is obscured by lack of memory. For example, one participant explained how he came into care at fifteen due to neglect and his parent's addictions. He was reminded by his care giver who was present that he was also in care as a toddler for the same reasons. He reported:

I came into care when I was 15, so for over a year. The reason is because my parents were dumb. My Dad fell off the wagon and the house was not clean enough. [The care giver interjected and advised that the parents have drug/alcohol related issues and stated that he was in care at age 2 till 3 ½ for the same reasons.] [Maxwell- 16 years]

Another participant was abandoned by her mother as a baby and given to extended family to be cared for. She reported her journey as one marked by abuse she had suffered:

I was 13 and in care till I was 18. I was abused, sexually abused, almost killed. I put myself in CFS, cause I was sick of that bull shit, getting hurt and stuff like that. [Mercedes- 20 years]

For those participants with memory problems, as is common with FASD, understandably, it was difficult for them to recall as adults, how they felt when they came into care as teenagers. Two of the older participants seemed affected by the questions about the reasons they came into care as adolescents. One participant said he did not remember why he had to leave his home at 17 but remembered being upset about it later in the interview and recalled having to go to the hospital afterwards. He looked down at the ground and seemed as if he wanted me to move on to the next question after remembering about being in hospital. Another participant who came into care due to abuse, presented as agitated with the questions and bringing up the past. She quickly moved us on from the question by saying that it was a hard time in her life but now her life is good. In both cases, I could tell participants were uncomfortable and so I moved on to the next question.

Placements

Participants experienced a myriad of placements in their journeys through care. For the most part, participants talked about their current living situations in positive terms. Participants had experienced a range of living situations, including hotels, shelters, group homes, foster homes, treatment centers, jail, proctors and semi-independent living settings. Common themes emerged regarding the challenges and strengths of placements. Emergency placements such as hotels and shelters were reported to have untrained staff who did not understand the young person and their needs, where every child tended to be

treated the same. One participant recommended more full time staff in emergency placements:

You could have the shelter more stable with more staff so they know what they are doing. More full time staff would have been the best, so they get what they need, more helping and learn ideas how to do it better and be more FASD friendly. Like most of the kids have their own mental challenges. [Sydney- 19 years]

A huge struggle for many was that they would vie for staff attention and end up getting in trouble or acting out when the attention did not come. Young people preferred places that had individual attention, such as one to one staffing or at least a high staff ratio so that they could do things with staff and get attention.

The proctor was probably the best placement with one male staff in an apartment. I had this in 2001 for about a half of a year. He gave me a lot of attention and there was always a lot of money to do fun stuff and that was what I really needed at the time. My staff let me make my own decisions like when we went shopping. He said that I could get what I wanted and then he paid for it. Plus, he was a good cook. He made some good East Indian dishes that I had never had before. That was good to try that and of course I made him bannock as well. [Raymond- 28 years]

The best placement was (specialized placement) because I had one to one staffing and it was easy for me and I could pretty much do what I wanted. I had one staff and I could do something fun. Eventually I got free time and they were trying to get me out to do things on my own. [Sydney- 19 years]

Research states that placements often break down in adolescence for youth with FASD (Brown & Bednar, 2003; Gough & Fuchs, 2008; Jones, 2003; Opie, 2003). Also, most frequently, the first placement was the longest for youth with FASD (Gough & Fuchs, 2008). Most of the participants reported their first placement being the longest and having a degree of stability in childhood. Most of the participants said they did not know why or did not remember why they moved from place to place while in care. One

participant talked about her journey through multiple placements which finally culminated in what she saw as a successful placement:

I had a whole lot of placements. I was in foster homes, hospitals, treatment centers, back in foster homes, hotels, shelters, group homes, back in and out of PY1(Psychiatric facility) until I found a good place that I really liked, which was Macdonald Youth Services.

(Specialized placement) was my favorite and I lived there for 3 years. When I was 17, I moved into my own place with staff and I didn't like it so I went back to one of the homes till I turned 18, then I had an extension from CFS, went to a hotel for a couple of months till I moved to Adult Services, which is 3 years ago now. [Mercedes- 20 years]

Specialized placements were the favored placement for four out of five of the participants. These placements usually had one to one staffing and low numbers of or no other youth in care. Each young person had access to their staff and received a lot of attention. They reported that they could do things and keep busy with staff and not have to wait or cancel plans due to the effects of other kids on them.

I think for people with FASD, supports really work well, preferably one on one and not so much a group home setting because then you are fighting for attention. And I could tell you stories about that too. So, one on one support works really well. And just be patient. I believe that I have taught the workers that work with me a lot about patience and what it takes to be patient with someone. [Raymond- 28 years]

Some of the young people reported the best placement to be one where the environment was set up in an FASD-friendly way. Sensory integration issues are a challenge for many children and youth with FASD (Schwab, 1999). Sensory integration refers to processing and organizing the sensory information received by our own bodies as well as the world around us (Schwab, 1999). This constant bombardment of stimuli can lead to overload and consequently result in some sort of out of control looking

behavior. Care givers and teachers can often interpret this behavior as hyperactivity, resistance, avoidance, or acting out (Schwab, 1999). What is really happening is that the person's brain is having difficulty making sense of the environment. Some of the participants who experience sensory integration issues and had some awareness of their needs in this area described the need for an FASD-friendly environment:

When you are working with someone with FAS, a key component is getting to set up the environment whether that be in school or where ever. I noticed how you asked me if I needed to close the blinds. Again, you were setting up the environment. So that's a really key component for me, cause that helps with the distractions. But work is very accommodating in setting up the environment and giving me tasks that I can do, and then of course accommodating the worker to be there as well. They are just there if I need them. So they don't have to be called in and then it is too late (if an issue happened). [Raymond- 28 years]

Just as long as it is relaxing, the color, the people that are around me most of the time if they are relaxed, that helps me. If someone's agitated and don't show it on the outside, I know on the inside. Just the way they sit too. [Kahmora- 18 years]

Other observations made in the research process that indicated the need to pay attention to the environment was being told by care givers that it might help for some of the participants to be able to choose which seat they would like to sit in during the interview. Another participant sat in a rocking chair throughout the interview to be able to keep calm and focus on the questions as his body has a need to move. We also shut his apartment window due to the loud traffic in the background. Another participant decided to sit in a comfy couch in a calming, quiet, and dimly lit therapy room. Making these accommodations seemed to help participants concentrate and remain comfortable and calm, as indicated by their presentation.

Independence

Experiences of moving out of care and the paths that young people with FASD take in the transition to adulthood are varied. Many participants were fearful of turning 18 and having to move on. For some of the participants, the transition to adulthood was a very confusing time and the transition planning process was difficult to understand. Participants felt that they had a say in decision making but were unsure what to decide as the process was difficult to comprehend. A common theme was “not being ready” to be on their own and just going along with what was decided by professionals. Each of the adult participants was transitioned with supports and services from Adult Services due to them meeting the eligibility requirements of having an I.Q. under 70. Many young people with FASD (diagnosed or suspected) are not provided with appropriate supports into adulthood due to ineligibility for services. Most people with FASD have I.Q.’s over 70 and a diagnosis of FASD does not guarantee adult services. Obscured by lack of memory and comprehension, the eldest participant explained what the transition was like for him:

I did not understand what was happening. But I did sit in meetings but I just didn't understand what they were talking about. I just went along with what they said. I didn't want anything to do with Family Services and Housing (Adult Services) but they convinced me that my life would be better and I've been with them ever since. It was hard for me to understand what that was going to mean for me at the time. [Raymond-28 years]

Another talked about her fears of being alone and not feeling like she had enough support in the transition:

I didn't feel like I had enough support. I just didn't want to go out of care because I was afraid to be out on my own which I still am right now but like, I was afraid to live on my own because it was just scary for me and I couldn't handle myself. And I wasn't ready to go out on my own just yet

*and I was nervous and so they put me into an adult services program.
[Mercedes- 20 years]*

The two participants who are currently in care (ages 16 and 18), were asked if they knew what the long term plan was for them in care and both said they did not know. The 16 year old was reminded by his foster mother that he told her that he might want to stay with her until he can live on his own one day.

Other research (Child and Youth Officer of British Columbia, 2006; Kleinfeld, 2000; Opie, 2003; Rutman, 1996; Streissguth, 1997) has shown that not unlike other adults with FASD, two adult participants in this study noted that one of the greatest challenges for them becoming more independent was managing money. Every adult participant had full or partial assistance with paying their bills, rent and shopping for food to ensure that their basic needs are met but most still experienced challenges with this. For example, when asked what was difficult about being independent, one participant reported:

Math, money sometimes, time limits on how long friends can stay and how long I can stay out, how much I should give people, how much I should eat and when I should eat. Trying to find money to pay the rent, food and hydro. [Kahmora- 18 years]

When I gave Raymond the \$20.00 stipend for sharing his story in the interview, he immediately gave it to his support worker. He advised that he gave her the money because:

When I have help with my money, I have money. When I don't have help, I don't have money. I have a co-signed bank account with the staff and we write out a budget together. Paying rent, food and other things by myself is hard. I would spend the money on something that I did not need. [Raymond- 28 years]

The adult participants were asked what would help with the transition to adulthood to make it easier. One of the adults was unsure and another felt that support in every area of life was needed.

Support in every area in a person living with FASD's life would definitely help with the transition. [Raymond- 28 years]

Another participant affected by chronic post traumatic stress said that she continues to be afraid to be alone as an adult and explained that she only takes a couple of hours of independent time from her staff in a 24 hour period.

I still need more time now I am not ready. Some days I feel like I just want to get out of here but I just don't realize that I don't want to move out just yet because I am so nervous and I don't know what to do on my own. When I am by myself, I don't know what to do. But I love (adult placement), they are like family to me you know. [Mercedes- 20 years]

THEME TWO: CIRCLE OF CARE

The circle of care for these young people along their journeys in care included foster and adoptive families, youth care workers, CFS social workers, coordinators of programs, therapists, correctional officers, psychiatric nurses, psychiatrists, doctors, support workers, employers, and teachers. Participants reported a range of feelings related to the care they received and the relationships they have had with care givers and professionals along the way. Family was found to be a sensitive topic for most participants, especially their biological families. *Circle of care* for every participant included some form of family structure such as extended, adoptive, foster or psychological family. Relationships with CFS workers for these young people with FASD were mostly identified as insignificant and for some, negative. Caregivers in more

specialized placements were reported to be understanding of the participant's needs and ended up being quite significant in their lives. Due to the myriad of care givers and professionals in the lives of these young people and the impact of their relationships on the youth with FASD, I identified circle of care as a second overarching theme. The sub themes coming out of young people's circle of care were: family, CFS workers, care givers.

Family

Talking about *family* always conjures up all sorts of feelings and reactions in people, including for young people in care with FASD. The majority of the young people in the study had no contact with their birth families since coming into care. Talking about birth families and especially birth mothers seemed to be a sensitive topic for most of the participants. Either participants avoided this topic or they warned me that it was a "touchy subject". I then moved on to another question taking my cues from them, not wanting to cause upset by the questioning.

Most of the participants had no contact with their birth families at the time of the interview and some had had none since they were taken from their birth homes in infancy. This parallels one study in the literature that found that it was most common for children with a disability in care to have no contact with their birth families (Fuchs, et al., 2005). One participant had made attempts to connect with his birth mother as many adopted children do and found that this was an upsetting event for him:

My biological family, I have no contact with them right now, but I am in the process of re-connecting with them. I did meet my biological mother back in 1999. Again, I set my expectations up too high and of course they came to an end. Plus, there was no one there to sort out our feelings with

each other. So, that was half the battle. It is kind of a touchy subject when I talk about my mom. I just kind of let people know that and I leave it at that. [Raymond- 28 years]

Another participant had not had any contact with her birth family for several years and had taken on a psychological family of placement staff, co-residents and friends. Evident in her response to whether she has contact with her birth family is the sensitivity of the issue for this young person and the need to focus on the present and her psychological family:

Hell no, no contact with them (birth family). I have my own family and that is (placement) and my boyfriend. Last contact with my family was 2005 but I don't really want to think about that. I'm in a good situation and I have a good life now. (Placement) is my family now. At least they feel like family. [Mercedes- 20 years]

Adoptive and long term foster families made a great impact on three of the participant's lives and continue to include them in the family circle, although they have not lived in the home for some time. This seemed to provide the participants with a sense of belonging and love as conveyed when they spoke about these families. One participant marked the significance of his adoptive family in his circle of care:

My adoptive family is very good. I keep in contact with my mom and dad a couple of times a week. You know we arrange visits and they have me over for family gatherings- they include me. I have 5 adoptive sisters and one adoptive brother and they had one child born to them. I see them at family gatherings. I don't see them on their own because we have kind of gone our own separate ways like what some families do. They are very understanding and patient, forgiving, loving parents. [Raymond-28 years]

Child and Family Services (CFS) Social Workers

CFS social workers play an important role in the lives of all youth in care and a critical role in the lives of youth in care with FASD. As guardian and case manager to youth in care, they are required to take responsibility for the care and planning with/for the young person and be involved in every aspect of their lives as a parent would. It is critical that the CFS worker understand FASD and how it effects the individual youth so that assessment, intervention and planning center around the young person's needs related to FASD. The responses regarding the relationships with CFS workers were varied. The eldest participant being 28 years old and having only been in care for a short while at age 17 understandably had difficulty remembering his CFS worker (s). He believed that his social worker only understood FAS on a medical basis but not how it affected him as a person. An insignificant relationship was reported in a few of the participants' experiences with their CFS workers. One participant had an insignificant relationship with one worker and experienced a closer and more involved relationship with another:

(1st CFS Worker) was at first when I was 12. (2nd worker): I didn't see him a lot. My Mom did most of the work with him. I used to see him more at the shopping mall. (Caregiver said that he did not make most of the meetings). (1st worker) took me for lunch and we talked about what I needed and how things were going and what would make it better. [Sydney- 19 years]

Participants were asked about whether they felt that their CFS workers understood FASD and how it affected them. Every participant reported that either their worker did not understand FASD or they were unsure whether they did because it had not been discussed. One participant conveyed how she felt about her conflictual relationship with her worker and how she did not feel that her worker understood her condition:

I don't really think she (CFS worker) does cause I don't really get along with her. And when we do start to get along, I butt heads with her non-stop. No she does not understand FASD. I only talk to her when I need something. She is trying to be something she is not. [Kahmora- 18 years]

Participants were asked what would make the relationship between CFS workers and youth with FASD in care better. Some of the participants felt that education and training for social workers on FASD would help to allow the worker to better understand FASD and how it impacted their client.

I would say to be more understanding and accommodating of the person with FASD by meeting their needs and not the needs of the organization. I think some more training for workers, the social workers. People like me could do presentations to them on what works for me and what doesn't work for me, things like that. [Raymond- 28 years]

Other participants spoke to the unavailability issue of some workers and the notion that this conveyed to youth in care that the worker did not care. Also, the need for advocacy and listening to youth were highlighted:

For them to actually be able to phone and visit, not to be so fake and actually understand me and their clients instead of assuming and making assumptions which aren't true. They don't know things about me that they should. [Kahmora- 18 years]

Work harder and help out their clients. When I need to talk or something I would just want the social worker to fight more for their client who they are there for. When I was a teenager, my social worker was hardly there, sometimes, every now and then. When I got to the point where I said oh, you are not doing your job, you're not helping me out, you don't care about me. Like seriously, do your job right. But social workers now a days need to help their clients out or even listen to what they have to say or what they have been through, cause I've been through a lot of shit. They need to learn how to listen. [Mercedes- 20 years]

Caregivers

Care givers have a significant role as parents in the lives of youth in care as they spend the majority of time with the young person and are critical in their care, safety, guidance and teaching on a daily basis. They are often what Dr. Sterling Clarren refers to as “external brains” (Buxton, 2004, p.109) of our children, adolescents and adults with FASD. Dr. Clarren explains that to one degree or another, depending on how severe the alcohol exposure, the child will require more guidance and direction than they can provide for themselves throughout the life span. Care givers of youth with FASD require support from their families, agencies, professionals and the community (Brown & Bednar, 2003; Frankel, Frankel & Opie, 2007). Alcohol affected children presented a range of complex demands involving not only all aspects of the child’s functioning, but also, community reactions to the child (Brown & Bednar, 2003; Frankel, Frankel, & Opie, 2007). This can be a high stress parenting situation, especially if the care giver has limited knowledge about the disability and lack of resources and supports to care for the youth.

In this study, participants spoke of their relationships with staff in various placements, schools, treatment centers and reported the qualities and skills they utilized that made them ideal care givers. Some of the participants spoke of the best care givers being those that were available to them, attentive, listened to the youth, were understanding, patient and accommodating. One participant conveys how her care giver accommodated her and understood her needs:

She (foster Mom) was understanding. When I was little we had to take naps and I would say, “I can’t sleep”. And she would say that it was ok and that I could come and sit with her. So, I would go and sit with her and we would just sit there and watch TV, read a book or talk. If I wanted a

hug she'd give me hug. She was understanding and nice. If I wanted to go for a walk she'd always want to know. She was protective. [Kahmora-18 years]

Being a “friend” was reported by a few of the adult participants as an important quality in a care giver. Many young people with FASD struggle with making and especially keeping friends (Berg et al, 1997; Copeland, 2001; Kleinfeld, 2000; Rutman, et. al., 1997; Streissguth, 1997) due to the primary disability of FASD, problems with social skills and behavioral difficulties. Some of the challenges with making and keeping friends relate to not reading social cues, being easily influenced, wanting to please, confabulations, not understanding cause and effect and trouble with abstract reasoning. For one adult participant, relationships with peers had been a string of negative experiences. He expresses his need for friendship in relationships with his care givers and explains how they have taught him the real meaning of friendship:

I call them (support workers) all my friends because they have shown me what friends are and what friends do. Whereas, I have had other people take advantage of me and this and that and abuse me. That is what friends don't do. They have shown me the difference between the two. So you know, I consider them more my friend than support workers. [Raymond-28 years]

Who is your biggest advocate?

I would have to say that my biggest advocate is (Coordinator of program). I have known her since 1998 and she's been the number one person in my life. She is like a mom to me. She looks after me and speaks to me in a very understanding and caring way- willing to accommodate just to see me happy. She just wants to see me happy. [Raymond- 28 years]

Another participant talked about several qualities in staff that helped him get through the challenges of daily living with FASD. He refers to different staff going

beyond the job, redirecting his behavior, changing the activity if it is not working and having a sense of humor.

She (staff) took me to a hockey game and did things that I liked. Even if she wasn't working she would come and take me to her games. (Caregiver reminded him about other staff). One guy (youth care worker) taught me about football he was an ex-bomber. He understood me. He said "Turn it around, come back when you are more collected". Or, "Go for a walk". He was clear and to the point. He would change the activity. (Caregiver reminded him about a staff's sense of humor). He remembers and starts laughing. He was the best jokester and would really get you laughing. He would make my day. [Sydney- 19 years]

Participants were able to contribute recommendations for care givers in order to facilitate the best care and a good relationship with young people with FASD in care.

Participants talked about styles of care giving, qualities of care givers and gave advice about how to work with youth with FASD:

I would say to them that they should really be understanding and patient with the person with FASD and accommodate. Because you know you are looking after their needs and not yours. And that they don't judge or get mad. I mean when I make the same mistake over and over again they tell me that it is ok and they help me get back on my feet. [Raymond- 28 years]

If they need space, give them space. Don't try to work your way to them. Most people that I know that have FAS, they will come to you when they are ready. If you push and push and push then you push them away and they never come back. Just stand off to the side like a parent would with their child and just wait. They will come to you and learn to trust you and pretty soon you won't be on the sidelines watching, you'll actually be right there playing the game with them. [Kahmora- 18 years]

THEME THREE: LIVING WITH FASD

Living with FASD is described in a myriad of unique and creative ways by young people with the disability. Several authors have elicited the stories of those living with FASD (Berg, et. al., 1999; Copeland, 2001; Kleinfeld, 2000; Mayer, 1999; Rutman, 1996, 2005; Streissguth, 1997). In this study, participants spoke of the experience and there was a range of knowledge and awareness among participants regarding the impact of FASD in their lives. Most were educated by their foster and adoptive mothers from an early age and repetitively taught about their disability and as issues arose, the connection between the issue and the disability. Those that were less aware of the impact seemed to have had less education from care givers and did not seem to fully accept FASD as a part of their life. Secondary disabilities were abundant for this group of young people and for some there were multiple issues. Some of the youth had several protective factors on their side which mitigated risk and some had many risk factors which elevated risk. The strengths, achievements and dreams of participants were explored and the findings suggest that youth with FASD in care find strengths in themselves and have hopes and dreams not unlike anyone else. Living with FASD was a significant phenomenon that came out of the interviews and due to this I have identified it as the last overarching theme. The sub themes coming out of living with FASD were: awareness and knowledge of FASD, secondary disabilities, and strengths, achievements and dreams.

Awareness and Knowledge of FASD

Many authors have spoken about the need to educate those with FASD about their disability from a young age (Lutke, 2003; Opie, 2003; Streissguth, 1997). Recent

research has cautioned care givers and professionals about talking to the young person with FASD about their disability as it can cause trauma and grief for the young person (Badry, 2009; Lutke 2000; Opie, 2003). Badry (2009) states that a specific set of supports and guidelines that address the experiences of trauma and grief which can emerge subsequent to learning this information are required. Adolescence is not an appropriate stage of development for children to be told about a serious disability, and particularly a disability that was caused by their birth parent's behavior (Opie, 2003). The preference would be to begin talking about the disability early in the protective stage of childhood, incrementally over a period of time (Opie, 2003). Discussing the disability with an adolescent who has just become aware that they have FASD requires consultation with an FASD specialist before a conversation begins.

In this study, participants spoke of how they came to learn about having FASD and what having FASD might mean for them. Those that had more knowledge and awareness of how their disability impacted them had a better understanding of what works for them, what does not and what their support needs were. Similar results have been found in other research (Lutke, 2000; Opie, 2003). They also could articulate what it was that support people did that helped them manage better in all aspects of life. The eldest of the group who was taught from an early age about FASD and how it affected him and who had been encouraged later in life to talk about how FASD impacted his life, had an awareness that shone through his interview.

I learned about FASD as a young adult, age 10-13. My adoptive mom explained FASD to me. She told me that my life would be very difficult and I would always need constant supervision. She said I would always be in trouble of some kind. She explained that why I am the way I am, is because of my biological mother's drinking has caused me to be this way and it is not my fault. [Raymond- 28 years]

Other participants had also been educated from an early age by their adoptive or foster mothers and had an awareness of how FASD affected them. One participant conveys her learning experience of what having FASD was like for her:

I was in grade 6 when I learned about FASD from my foster mom who I call "Mom". I was diagnosed with FAS at birth. I asked her how come kids pick on me and how come I don't learn fast enough. And she would tell me and explain it to me. Since grade 6 I have had a fascination with it. The fascination died away and I decided to accept it. My foster Mom just said that my brain wasn't fully developed when she (birth mother) did that stuff and I had a bit of brain damage. I can't learn, pick up things and comprehend things as fast as other people. [Kahmora- 18 years]

One participant was impacted by memory to a degree that retaining this information and recalling it in that moment was very difficult, without the care giver helping them to remember.

My Mom, my adoptive Mom told me. I am trying to think, it was a long time ago. I think I was 2 or 3, I am estimating. (Pause) Caregiver interjected and advised that he always knew from the time he would talk. It was bits of information and he would ask questions about it and I would answer it. In time, he learned about it. I don't know what his full understanding of it is, but he grew up with talking about it in conversations with me and my friends. It has been an active part of his life. [Sydney, 19 years]

Others had limited education from care givers about their disability and had not come to accept FASD as a significant part of them.

I was young. My brother was diagnosed young and he was in special programs. He has more bad FAS. Caregiver interjected and said that he has more physical signs (facial features). I don't know if I have a diagnosis. Caregiver stated that everyone knows he has it but they do not know if he has a diagnosis. He was born out of province and came here at

age 2. They knew as a young child he had it and he had Children's Special Services involvement. He has wanted to know more about it since being told he has it. [Maxwell, 16 years]

When asked what FASD felt like, the uniqueness of individuals and of the disability was revealed when participants responded:

To me, it feels like there's always a thunderstorm going on in my brain. A lot of things are hard for me. Saying no to people, impulsivity, not being able to see the big picture, going to and from places alone- I get lost. These things are hard for me. [Raymond- 28 years]

I just treated it like I was (pause), I just took it as ok, FASD, so what. I have challenges in my daily living and it is hard to do some things and some abilities are there and some aren't. My thinking and my memory are not there like they would be if it was normal. I am kind of scattered all over the place because of the ADHD. My memory is not good, that if I said something, I would forget a minute later. [Sydney- 19 years]

Secondary Disabilities

As talked about earlier in the literature review, secondary disabilities refer to those difficulties that a person with FASD is not born with, that could presumably be ameliorated through better understanding and appropriate interventions (Streissguth, 1997). Mental health problems, disrupted school experiences, trouble with the law, confinement, alcohol and drug problems, dependent living, and unemployment were explored with participants and the results were alarming. Inappropriate sexual behavior was not explored for ethical reasons. This is a complex, confusing and sensitive issue for individuals with FASD that had the potential to open up a myriad of issues and could have had a detrimental effect on the participants emotional well being and on the remainder of the interview. For information purposes, in Streissguth's (1997) study, 52%

of adults with FASD had inappropriate sexual behaviors. Inappropriate sexual behaviors were reported to be sexual advances, sexual touching and promiscuity (Streissguth, 1997).

Streissguth's study also examined protective and risk factors as discussed earlier in the literature review section. Protective factors mitigated secondary disabilities and risk factors elevated them. Some of the young people in the study had several of the protective factors and some had many of the risk factors and less protective factors. All the youth presented with an abundance of secondary disabilities although there was found to be a balance of protective and risk factors between participants.

Mental Health Problems (and Confinement)

Mental Health issues were found in 90% of individuals in Streissguth's longitudinal study on secondary disabilities (Streissguth, 1997). Strikingly, all five of the participants in this study had mental health issues and all at one time or another have taken psychotropic medication. Famy, Streissguth, & Unis (1998) concluded in their study that adults with fetal alcohol syndrome and fetal alcohol effects suffer from substantial mental illness. The most common mental health diagnoses that the young people had were Depression (5/5), Anxiety (4/5), and Attention Deficit Disorder with Hyperactivity (ADHD) (3/5). Four out of five of participants had been confined to a treatment/crisis or psychiatric center in the past due to their mental health. A few participants had multiple mental health diagnoses on top of their medical FASD diagnosis. This was also common in Fuchs et al study (2005) whereby they found that

46% of youth with FASD had an additional mental health diagnosis with the most common being ADHD.

Yes, I have had problems with mental health. I take medication for Depression. I was in Grace Hospital when I was 17/18 because I was out of control when I had to leave my adoptive home. I stayed there for a half a year. [Raymond- 28 years]

Yes, I have had mental health problems. I have been suicidal in the past. I am diagnosed with Depression, Anxiety, ADD, ADHD, and OCD. A physician diagnosed me when I was 12. I have spent time in the CSU and PYI because of suicidal ideation. I sometimes stayed 2-3 weeks or longer. [Kahmora- 18 years]

I am not sure if I do. (Together with his care giver) he says Bipolar, OCD, Partial FAS, and ADHD. [Sydney- 19 years]

Participants were asked about their experiences in treatment and crisis centers. Some had spent a lot of time in mental health facilities and others had never had this experience. It was difficult for the young people to remember their experiences with staff in these facilities because of the brevity of their visits. One participant conveys her experience with mental illness and her many moves within the mental health system:

I have post traumatic stress disorder. I have for a lot of years. I can't really remember what the doctor said about that. My anxiety is really bad sometimes when I usually go out in public. It makes me want to freak out but I just hold it in, just so like I won't freak out. It feels like everyone is looking at you but I just learned to deal with it lately. I pretend that I don't have anxiety. I know I had Depression before too. And they said FASD. I have been in a crisis unit many times and PYI too. I was there each time because I was suicidal/ trying to kill myself and that was the only reason. I was there for a couple of weeks each time. One time I was in PYI for two weeks and then I was transferred to MATC (Manitoba Adolescent Treatment Center) for 3 months. [Mercedes- 20 years]

One participant recalls his frequent trips to the hospital but has trouble remembering mental health troubles and is reminded by his care giver:

I have never been in a crisis unit or psych ward but was in the hospital for seizures lots of times. No, Depression and other stuff has not been a

problem for me. The caregiver interjected and said that Depression and Anxiety have been problems for him and that he is medicated for seizures and sleeping aides as he can not sleep at night without them. He has been on Concerta, Dexdrine and Ritalin (for ADHD) but they did not work so they did not give them to him. [Maxwell- 16 years]

Dubovsky (2006) alerts professionals and care givers of those with FASD of the frequency at which this group of disabled adults are misdiagnosed with mental health diagnoses due to the invisibility of FASD and the symptoms presenting similarly to mental health issues.

Disrupted School Experience

How individuals with FASD learn and their experiences in school have presented a significant challenge to individuals with FASD, their care givers and teachers. In Streissguth's (1997) study, 60% of participants had disrupted school experiences. Most of the participants in this study disclosed challenges in learning and every young person disclosed having a difficult school experience. They also verbalized what helped them to learn and what caregivers did that assisted them in learning. Similar research has been conducted and shown that young people with FASD can verbalize their experience with learning and provide suggestions for making it easier (Healthy Child Manitoba, 2007; Kleinfeld & Shiban, 1993; Streissguth, 1997). In the current study, many participants reported having challenges with learning. Participants' experiences of learning are conveyed in the following passages:

Learning for me is very hard. For me, I always feel like I have to learn things the hard way. I always like to call it being dragged through the mud. And, in the past 10 years I did learn a lot of stuff. I am thankful that I learned at the time. And some things I am still trying to learn. But I was told that people that have FASD sometimes it takes their whole life for them to learn that. [Raymond- 28 years]

Yes, learning is hard for me. What makes it easier is when people break it down for me and have a simplified explanation and not so much at once. Once I get it done, then I can go to the next thing. That is what my teachers do. [Kahmora- 18 years]

Many participants spoke of struggling with their school experience throughout their childhood and adolescence. One participant spoke of challenges with abstract reasoning, transitions and distraction that got in the way of him attending classes:

School was very hard for me, especially in high school because a lot of things were abstract and the transition from going from one class to the next because now I know I needed support on this. Whereas I was very distracted by someone or something on the way to class I never went to the class. [Raymond- 28 years]

Another participant talked about her experiences with being bullied and having to be monitored by a school staff for most of the day to stay safe:

When I was younger it was very agitating. I got picked on a lot, cause I'm different. You didn't know why. You didn't know why you had to have these special programs. And I would try to find a safe place but there was no safe place because the bullies would follow me. Every morning was a freak out because I didn't want to go to school because I'd get beaten up pretty bad. I spent most of the day walking around school with my Principal and everyone would call me the teacher's pet and that was only to keep me safe. [Kahmora- 18 years]

Participants had different experiences with teachers with some being a good experience and others presenting a challenge for young people. Some participants reported that qualities such as being understanding and flexible were helpful:

The teachers were understanding. Because when I needed a break one of my teacher's would be like, "You need a break?" I'm like Yah, and they'd let me go. They are still like that to this day if I need a break. I don't even have to say it to them. I just look them and they say to go ahead. When I am pacing, they know I need a break. [Kahmora- 18 years]

Grade 5 was as far as I can remember. That was a very good year. I had a one to one. From there I went to another school. These teachers looked after me very well. Caregiver adds that even when a teacher was assaulted by him, she still worked with him and she even moved schools when he moved in order to work with him. [Sydney- 19 years]

Other participants had positive and negative experiences with different teachers depending on their styles, personalities and understanding of the young person.

I don't like teachers. I don't like them beside me all the time. I used to get sent to the office for getting in trouble so I did not have to be in the class. Grade 7 was the worst and I had lots of suspensions. But, something good about the teachers is that they keep me on task. Caregiver advised that he had an IEP after a month of non-attendance due to being overwhelmed with work plans that he could not understand. They gave him regular work in the first few days and scared him and he refused to go to school. [Maxwell- 16 years]

The teachers...it kind of depended on the teacher for me. Some teachers really understood me as a person that they could see that I was struggling in school they kind of gave me a little more leniency. And other teachers they just kind of kept going with the year whether I was behind. They were there just for the job I guess. [Raymond- 28 years]

Trouble with the Law (and Confinement)

Streissguth (1997) found that 60% of adolescents and adults in her study had trouble with the law. All of the participants in this study had trouble with the law at some point in their adolescence. Two of the participants had never been charged with a crime however, had committed mischief and arson related “crimes” and were spoken to by police. They were never arrested and detained. The other three participants had been arrested and detained at the Manitoba Youth Center (MYC) on one occasion each. These incidents were related to theft and assault on staff. It was difficult for them to remember their experience in the institution due to the brevity of the incarceration and the time

lapse that had occurred. Most of these incidents occurred in the early teen years. Two of the participants talked about the reason that they went to MYC on one occasion being that they assaulted a staff at their placement:

Yah, I was in MYC when I was about 13 or 14. It was the same issues as why I came into care, except this was at Marymount. I got a little moody and the rage got the best of me and I assaulted somebody. [Sydney- 19 years]

I was at MYC one time when I was 14 for assaulting a staff at the hotel that was working with me. I was only 14. You know we do stupid things. We've all done stuff that we are not proud of. I was there only one night and then my social worker came to get me. I was just having a really bad night that night. [Mercedes- 20 years]

Another youth that had not had to spend time in jail, explains how he was curious and was playing with a sparkler which ended up lighting the house on fire. His trouble with the law was related in his story:

I almost ended up in MYC because of arson. Our house went on fire but I told the police the truth and that is why I did not have to go to jail. It was accidental. I lit a sparkler and put it in a hole in the roof and it started the fire. [Maxwell- 16 years]

Alcohol and Drug Problems

Addictions are a prominent issue in our society and certainly in the child welfare system. In Streissguth's study (1997), 50% of males and 70% of females had trouble with addictions. In the current study, one male admitted to having trouble with alcohol and drugs as an adult but not as a youth and both females admitted to having issues with both alcohol and drugs in adolescence and adulthood. Out of the two participants without issues with addiction, one reported only trying drugs and alcohol and smoking, and the other said he has never used any drugs or alcohol. The two female participants abused

alcohol and drugs frequently to the point where their life was placed at risk. Their stories of struggling with addiction are expressed here:

I did used to do drugs some time ago, but I have been drug free for a while now. I haven't been smoking for over a year now. I used alcohol up until last week when I drank too much and had a seizure and ended up in the hospital. I got all bruised up and stuff, but it is gone now. They had to call paramedics because I was unconscious. They tried waking me up but they couldn't. I had alcohol poisoning so they had to pump my stomach. My friend was crying. Drinking has been a problem for me but I can't touch the stuff because of what happened. [Mercedes- 20 years]

One time I was freaking out. I was on a whole crap load of meds and one day she (foster mom) found me in the kitchen with a butcher's knife, cause I was all doped up and at the time I was popping pills. At the time, she said I did a lot of crazy crap and stuff because I was high. I set fire to one of my houses I used to live in and we had to move. I broke a few windows, broke a light shade and my door because I was too high on my meds. [Kahmora- 18 years]

Both female participants expressed their inability to gauge how much was too much and their tendency to follow the crowd and be unable to say no to people influenced their decision to use substances.

Dependent Living and Unemployment

None of the participants in the current study live independently due to their high support needs. The minimum amount of hours of staffing for the participant population was 9 hours per day and the maximum amount was 22 hours per day out of 24, other than the youth who had full supervision. In Streissguth's study (1997), 82 % of adults with FASD were unable to live independently. The current study found 100% of young people with FASD to be living dependently. These findings are critical to our assessment regarding young people with FASD in care transitioning to adulthood. It provides more

evidence for the need for continued government care and support after age 18 for this population.

The findings regarding employment for this group of young people were also in line with Streissguth's (1997) study. She found that 70% of adults had difficulties with employment. One of the young people had never worked but volunteered. Another had worked in restaurants but was not currently working. Out of the three adults that were working at the time of the study, two of them worked in a supported and protected environment in an agency where they understood the disability and the needs of the young person. Also, staff was available to the person if an issue arose during their shift. One adult had initiated his application with a restaurant in the city, got the job on his own accord and had maintained it over time without additional supports in the workplace. The workplace is aware of how the disability impacts the participant to a certain degree.

Strengths, Achievements and Dreams

The more time one spends with young people with FASD, they realize that although there are great challenges, FASD is only a part of who they are. Most people with FASD have the same hopes and dreams as anyone and they have strengths that they are able to identify in themselves. If they can't see their strengths, it is our job to bring those out and help them see their strengths and achievements so they can feel good about themselves. More often than not, people are focusing on the limitations and problems with the person with FASD when working with them. We need to always remember the good and include the strengths of young people in our assessments of them. However, we do need to be cautious with basing assessments solely on strengths and abilities which

sometimes translates into unrealistic expectations of the young person and can actually place them at risk. Often, the lives of those with FASD are filled with many challenges. Lutke (2000) reminds us of the importance of developing a strong sense of self-worth in alcohol-affected children. As Lutke's daughter put it, "I may not be able to go to College, but I am a very good dog groomer". In this study, participants were asked about what they are good at, their achievements and their hopes and dreams. Participants conveyed their strengths in the following stories:

I am good at singing, writing poetry and playing the guitar. I am proud to be alive, proud of my life, proud to be working and being paid ten bucks an hour. I am making the coin. I try to save money to go out and get something to eat or go to Starbucks and write. [Mercedes- 20 years]

I am good at keeping things clean like my apartment and myself. If I have things to do, I do them on the spot and get them done. I am good at reading people and their body language, getting vibes from people, and helping them with relationships. I am a listener, mediator and helper. [Kahmora- 18 years]

Like I found the job at (restaurant) and I am pretty proud that I got through the system and ended up going to (another location). I hope to cut down my staff hours to be on my own one day. My goal was always to be alone in my own apartment. [Sydney- 19 years]

Young people talked about their dreams in life and many of them involved having a family:

My main dream is I have two beautiful daughters and my dream is to eventually get together as a family. I see them when I can, when it works out. [Raymond- 28 years]

I would like to have a house, go traveling to the states, Bahamas or Cuba. I would like to have my own family when I am older. I only want one kid. One's enough twice is a curse. [Mercedes- 20 years]

Participants were asked about what advice they would give to youth with FASD that are coming into care for the first time. As experts of being in care and having been through the journey, the young people were well placed to provide advice to other youth coming into care. Some responded with advice about acceptance and others encouraged youth in care to tell staff what they need and know that the staff is there to protect them and the journey will be ok in the end.

The advice I would give to other youth is just accept your life the way it is and just accept the support given to you and your life will be much better. [Raymond- 28 years]

Be patient. If you need space, say something. If you need attention, say something. Cause acting out doesn't get you anywhere. It's embarrassing after a while and people you know or potential friends- they could make fun of you. If you need something, tell someone. If not, write a note to the staff about you would need and they will help. [Kahmora- 18 years]

Oh, what advice? I would say it is going to be a little bit rough at first but once you get used to it it's going to, your going to learn more. You are going to realize, oh this is really hard, I can't stand living here. I hate it. Oh, I am going to smash this, I am going to smash that. No, Just don't give up you know, cause they are here to help you and protect you. They are here to listen, not harm you. Just take a breather, you'll be fine. I was nervous too, you know. But I got used to it after a while you know. I got comfortable, I was shy at first. I was shy to speak. Yah, I would tell them a bit about my story. [Mercedes- 20 years]

Conclusion

In this chapter, I have provided an in-depth analysis of the experiences of the participants who have FASD and are or have lived in care. In exploring concepts of journey through care, circle of care and living with FASD and the sub themes that they envelope, I found many findings in this study that paralleled similar research in the

FASD field regarding the experiences and needs of young people with FASD. As well, new information came out in this study specifically about the experience of being in care for young people with FASD from their perspective, as this is a largely unexplored area in the research. The similarities to the literature and new findings in this study lend themselves to some specific recommendations, which I will speak to in the following chapter.

Chapter 5

Discussion and Recommendations

Discussion

The findings in this study regarding young people with FASD and their journey through care mirrored many of the findings in the literature. Most children with a disability initially come into care because of their parent's conduct, much of the time due to substance abuse issues (Fuchs et al, 2005). This was the case for all of the participants in the study. Placements in care for those with FASD are known to be problematic and there are a high number of placement breakdowns with this population of children in care (Jones, 2003; Opie, 2003; Brown & Bednar, 2003). Multiple placements were an issue for many of the youth in this study. Not unlike the outcomes of other similar studies, (Gough & Fuchs, 2008; Schibler & Newton, 2006; Child and Youth Officer of BC, 2006) the transition to adulthood was fraught with challenges for all of the adults who had transitioned in this study. The average young person with a typical brain is confused by what is needed and expected upon moving out and entering the adult world and it is almost inconceivable to those with a disability. Every participant lived dependently and had full or partial assistance with every facet of their life, including finances. Some of the young people were fortunate to grow up in more protected environments with people who understood FASD and consequently, planned for their transition and connected the young person to adult services. The adults in the study said that they had trouble understanding what the transition meant for them and the planning process, therefore allowed workers and care givers to plan for them at the time. The younger participants, still in care, were not sure what they needed in order to transition from care.

The findings regarding the circle of care for young people with FASD were similar to what the literature says and also to my experience working with youth with FASD. With regard to family, the literature states that it is not uncommon for children in care with FASD to not have any contact with their birth families and also to become permanent wards of the child welfare system (Fuchs et al, 2005). The inquiry into contact with birth families was a “touchy subject” for many, avoided by some and remains an emotional issue for most. The study found that young people had continued adoptive or foster family involvement, extended family involvement and in one case, a psychological family structure was reported as a support. Relationships with CFS workers were found to be mostly insignificant, for some negative and for one neutral. Participants felt like their workers either did not understand FASD or they were uncertain about their knowledge of FASD as it had never been discussed. Care givers were found to have a significant role in the lives of these young people, especially those that had some understanding of FASD and worked in an FASD-friendly manner with the young person. Participant’s experienced a myriad of care givers in different settings and some were able to articulate the qualities and styles of care that worked best for them. The majority of participants requested that they have a care giver present during the interview for support which shows their significance. The care giver also provided an “external brain” for the young person to help fill in missing information. Mc Creight (1997) recommends this type of three way communication with the young person with FASD to allow information to pass accurately and in turn, provide appropriate intervention.

The findings with regard to living with FASD were similar to the research literature as well. Some participants had some awareness of FASD and their needs partly

due to care givers teaching them from an early age about the disability. These folks were aware of what worked for them and what did not and could verbalize this. Those with less knowledge of how FASD affected them had less to say about what worked for them and what did not. These findings are in line with other studies that encourage care givers to teach young people about the disability to assist the person with FASD understand their needs (Opie, 2003; Lutke, 2000).

The secondary disabilities of the young people in the study were abundant, which parallels the research literature on secondary disabilities in adults (Streissguth, 1997). Every participant struggled with mental health issues, trouble with the law, disrupted school experience and dependent living. Most struggled with addictions and those that were employed, all but one had very protected environments with employers who understood FASD and staff was available to the young person if issues arose. Although the secondary disabilities in this study were substantial, the young people were able to find strengths in themselves and reported having goals and dreams for themselves. Other research has heard from other young people with FASD talking about their strengths (Berg, et. al, 1997; Rutman, et. al., 1996, 2005). The importance of talking about strengths with young people with FASD has been reported in other research as well (Jones, 2003; Kleinfeld, 2000; Lutke, 2000; Opie, 2007; Streissguth, 1997).

In summary, many of the findings reveal similar themes in prior research regarding youth in care with FASD and young people with FASD in general. With some of the challenges for this group of young people in care presented in this study, the following section details some recommendations regarding best practice for young people with FASD.

Aboriginal Youth in Care

It is imperative that a discussion occur regarding our Aboriginal children and youth in care. Manitoba's child in care population reflects an over-representation of Aboriginal children. The reasons for this over-representation have been acknowledged to stem from historical events, most significantly colonization, residential schools, and the subsequent intervention by the mainstream child welfare system (McKensie & Morrisette, 2003), resulting in the disconnections from language, culture and family (Fuchs, et al., 2005).

Fuchs, et al. (2005) found that 70 % of children in care in Manitoba were of Aboriginal descent and out of all children in care that were found to have a disability, about 70% were Aboriginal. Out of those children that were found to have FASD as a disability, an alarming 94% were of Aboriginal descent. I think that the issue of under-referring non –Aboriginal children for an FASD assessment has something to do with these statistics. Non-Aboriginal children with a disability were more likely to have a mental health disability or other medical disability. I think that the questions about drinking during pregnancy might be asked more frequently and freely to Aboriginal mothers by social services providers. The study also found that 45 % of those children in care with a disability have no contact with family.

In summary, what this is telling us is that the majority of children in care are Aboriginal, all but 6% of our children in care with FASD are Aboriginal and half of those children are disconnected from their families. These are very alarming statistics. In addition to these statistics regarding child in care and FASD, there is an over-representation of attempted and completed suicides (Schibler & Newton, 2006) and

incarceration (LaPierre, personal communication, 2005) for Aboriginal children. This frightening picture of the reality for our Aboriginal children and youth needs immediate attention by the child welfare and other systems working with them.

In the current study, 80% of participants were of Aboriginal descent and none of these young people had regular contact with their birth families at the time of the interviews. Two participants had sporadic contact with birth siblings and one had made an attempt to re-connect with his birth mother but it was unsuccessful. The participants were not asked directly about being Aboriginal or about their culture in this study. This was of interest to the researcher however the researcher already was concerned about the breadth of questioning regarding being in care and living with FASD being too much for the young people. Two participants mentioned their belonging to an Aboriginal hockey team and working in an Aboriginal organization of which they spoke to with pride, so there was some cultural involvement for some participants. I think that one reason that the subject of culture did not come up more than what has been described is because I asked concrete and direct questions regarding the experience of being in care and living with FASD and participants stuck to the question at hand. The youth were advised from the outset of the research by their care givers and then by the researcher that the focus of the research was about living with FASD and being in care. Recommendations regarding Aboriginal children in care with FASD follow in the next section.

Recommendations

Introduction

The following section will speak to the recommendations that were formulated with some input from participants in the study to improve or expand on the current services being provided to youth in care with FASD. My findings fell into three main areas: journey through care, circle of care, and living with FASD. I make recommendations in relation to some of these areas and how practice and policy could be changed and will conclude by discussing areas for future research that could build on the work already undertaken in this study.

From my experience as a social worker having worked with many individuals with FASD over the past 18 years, there appear to be three strains of concern regarding people with FASD coming into contact with the child welfare system. The first involves those young people that are alcohol affected but are not identified to the systems as such. They may enter care with several mental health diagnoses, may have never been assessed by anyone before, or may present with some of the symptoms of FASD but labeled as a behavioral problem. The second involves those young people with a formal medical diagnosis of FASD or suspicion of having the disability that end up receiving services or land in care. The third are parents with FASD who are not the focus of this study but are considered to be another group of those with FASD who are being unidentified and neglected by the system.

Screening for and Identifying FASD

The invisibility of the disability is even more of an issue for the group of young people who are alcohol affected but not diagnosed due to their non-identification. If you were to ask an average CFS social worker whether they had a youth or parent with FASD on their caseload, if there were none with a diagnosis, likely the answer would be “No”. And if you were to ask a worker if they felt that their client had cognitive difficulties, unless the client presented as mentally challenged, they would likely say, “No”. This is to say that many social workers are not trained in what to look for in order to identify those with FASD. Therefore, our folks with FASD who are not identified get misdiagnosed, misplaced and misunderstood.

We know that when this happens, the secondary disabilities of FASD escalate and for our kids in care, it also means that they experience multiple placements. Further, these young people often leave care unprepared and end up in a cycle of poverty, homelessness, incarceration and early parenting. The high number of children coming into care due to their parent’s drinking and drug use should alert us to the possibility that we are working with children and families affected by FASD. The recommendation here is for FASD to be considered among the diagnoses or issues for the person that is presenting with some of the characteristics of FASD and to have the person assessed appropriately. Preventing iatrogenic damage to a population of individuals disabled with FASD requires that social work professionals recognize the possibility of the presence of this disorder in certain individuals, and requires that social workers modify their practice methods and theories to accommodate the realities with which this population lives (Opie, 2003). If a formal FASD assessment is not able to occur, then consultation with

an FASD Specialist in the community or within the agency should occur if the worker is not trained to do so. If there are clusters of characteristics and red flags present, then intervention and planning should be tailored to the needs of the client based on what the presenting issues and symptoms are. According to the Child and Youth Officer of British Columbia (2006), the Ministries of Children and Family Development, Education and Health are involved in a cross-ministry initiative aimed at developing a functional assessment tool that would be designed to assess the adaptive functioning of the individual with FASD in order to determine what types of services and supports the person requires. Another initiative in BC is the development of a provincial network for the screening and assessment of complex developmental behavioral conditions (Child and Youth Officer of British Columbia, 2006). This province should follow suit with what British Columbia is beginning to do with regard to screening and assessing needs for its population of people with FASD.

Better Care for those with FASD

Young people with a diagnosis of FASD coming into care have some advantage over those who are not identified as such. Because they are identified as a person who has a disability, they are expected to have challenges in living. However, for this group often their care givers and the people in charge of their care have a limited understanding of FASD and lack of resources to care for them. Some have a “one size fits all approach”, whereby the thought is, “Oh, she has FASD, then we do this”. If one spends any length of time with individuals with FASD, one quickly learns of the uniqueness of each person and remembers the uniqueness of everyone’s brain. A unique brain, with

unique exposure to alcohol, with unique impairments and unaffected areas, has unique needs and requires unique intervention.

Assessment and Intervention of Youth in Care with FASD

When we have a person with FASD on our caseload, we need to go back to their FASD assessment if it is available, and look at the recommendations by the doctors. Consultation with an FASD specialist with the Manitoba FASD Center should be sought out regarding what we know about the client's unique brain. We need to know which of the nine brain domains that were assessed, have been affected and what the recommended interventions are based on this assessment. Also, at the point of entry, what mental health diagnoses and other secondary disabilities are also present and the impact of the interventions (behavioral, medicinal) that have been used. If there is no FASD assessment report available, psychological, occupational therapy, speech and language pathology assessments by someone knowledgeable about FASD should be conducted and care givers should be interviewed about the person's unique needs. The functional assessment talked about earlier in the last section, should be created and used to determine the adaptive functioning of adolescents and adults with FASD in order to establish the supports and services needed. The client should be referred to FASD services in the community. When making decisions with and for clients, they should be based on their developmental level rather than their chronological age. If they have not been taught about their disability, this process should begin. The Manitoba FASD Center has professionals that teach care givers to talk to young people with FASD about their disability. Research shows that this is critical to their awareness and understanding of

themselves and the process of learning what works for them and what does not so that they can teach us (Opie, 2003; Lutke, 2000).

Appropriate interventions will decrease multiple placement issues and secondary disabilities in these young people. Other systems involved with the young person during their time in care, also should follow the same guidelines. The FASD-friendly care plan should follow the child wherever they go. In our assessments of kids and families, ask what works for them and use the said intervention and throw out what doesn't work. We also need to remember that every person has strengths and can achieve goals with support.

Case Management- Working Differently with Clients with FASD:

“FASD does not excuse behavior, it explains behavior”. (Dan Dubovsky)

Along my journey working with people with FASD, there have been many occasions where other professionals and care givers say to FASD advocates, “you’re coddling them, letting them get away with their behavior, how are they ever going to learn”? Working with people with FASD requires a shift in thinking, what Diane Malbin calls a “paradigm shift”. For instance, when a client with FASD is late or misses an appointment with their social worker, often the client is treated like everyone else and might have to re-schedule the meeting and be sent away. They may be thought of as irresponsible, disorganized and sometimes are perceived that they don’t care. If the social worker understands that they have FASD (brain impairment), which might affect their perception of time, their internal locus of control, ability to organize and plan ahead, they will then understand why the client sometimes is late or misses appointments

without some accommodation in place. A reminder call an hour before the meeting time, or providing a support worker to assist might help as well as transportation set up for them. If a client comes late for an appointment perhaps the worker could still try to accommodate the client by fitting them in. If we understand that the undesired behavior is not purposeful or intentional and understand the underlying cause is brain damage, then we will make appropriate accommodations for the person with FASD. This is not coddling or “letting things go”. This is making accommodations for a person with a disability and understanding that they are functioning at a younger developmental level than their chronological age. If we had a client who was visually impaired, we would ensure that we guided them through the building to where we were going to meet and make sure they were comfortable and were able to leave the office safely by helping them out and making sure that they had appropriate transportation. We would also feel empathy for their situation and the challenges they face due to their disability. We need to do the same for individuals with FASD.

Recommendations Regarding Placements

There are many challenges for young people with FASD regarding placements in care, including placement breakdowns. Every participant struggled through their introduction into care in emergency placements in an overwhelmed system. For any child, not just those with FASD, the least amount of placements is recommended. Many times, young people with FASD do not know why they move from place to place or can't remember why. The literature identifies stability in placements and education and a

lasting relationship with at least one adult support as important to successful transition from care (Fuchs, et al, 2007; Jones, 2003).

Our youth with FASD need regular and consistent staff teams, care givers specialized in FASD, with a high staff to client ratio. Participants spoke of their need for attention and the consequences that occurred when attention could not be provided. This speaks to the need to work with them at their developmental level rather than their chronological age. Being developmentally younger, they require more attention and support than a typical teen. They spoke of care givers not understanding FASD and their needs and different staff with different styles coming and going. A couple of participants who are aware of how the environment effects them, had suggestions about setting up the environment for better placements and school settings. An occupational therapist can be contracted to help conduct an environmental adaptation.

Recommendations for Education

Participants spoke about having lots of troubles in school and learning. They made mention of things that teachers did that were helpful and made recommendations on how to make learning easier and the school experience more successful. Some participants said that repetition and breaking it down made it easier to learn. If a mistake was made over and over again, those that were not judged and were just helped to get back on their feet said that this was helpful. Participants spoke of things being too abstract and making them more concrete was helpful or providing a simplified explanation. Often they are easily distracted and sometimes forget what they were supposed to be doing for example during transitions between classes, therefore need to be

helped to stay on task. Moving at a different time than the traffic might be a helpful solution. Taking a break away from class, using a calming space or an OT room was helpful as well. Bullying, not understanding work plans and a stressful environment were some reasons for non-attendance.

We can see from the information the participants provided, that they often know what works and what doesn't in this learning environment. Listening to the young person with FASD and making a plan based on what they are telling us about what works or does not work, might be the key to a more successful school and learning experience.

Recommendations for Caregivers

Along with home and school placements, there are many stories about the challenges and strengths of staff and other care givers. Participants described several positive qualities about staff and verbalized the best way to work with them as individuals. Staff that was knowledgeable about FASD, patient, understanding and accommodating was best suited to caring for these young people. These are often the care givers found in specialized placements. Often in regular, less specialized placements we see a poor fit between youth with FASD and staff. Staff are often not trained to work with those with this disability and do not understand the brain = behavior equation. Youth should be worked with at their developmental level and not according to their chronological age. The need for individual work, 1 on 1, and a lot of attention was a common theme among participants. Changing the activity or changing something that was not working and "trying differently" was noted to be helpful. Some participants reported that staff were considered "friends" because they were unconditional, safe and

did not hurt the young person emotionally. As care givers, we are taught to have boundaries with youth in care and not be their friends. If we work with this group of young people in care on their developmental level, we will come to understand their perception of us being seen as their friend or family. One participant had no family members in her life and had a psychological family made up of her staff and co-residents. Some of the young people are saying that they took comfort in this relationship and it was very significant to them. Perhaps we need to re-assess how we relate to youth with FASD in care and hear their call to be a friend or be like family to them.

Recommendations for Child and Family Services

The majority of participants reported an insignificant or negative experience with their CFS workers. The eldest participant was unable to recall the relationship with his CFS worker fully but he felt that she understood FAS on medical basis only rather than understanding how FASD affected him as an individual. A few participants spoke of their workers being unavailable to them and feeling that they did not care because they did not call or visit. They did not feel that the workers listened to them. They recommended that workers listen to their story of why they are in care, advocate for them, protect them and pay attention to them. Regular phone calls and visits were recommended by most participants. Being trained in FASD was a recommendation from some of the young people, specifically being trained first hand by people with the disability.

As a CFS intake worker I am painfully aware of the reality of not being more available to clients, especially our kids in care. Unfortunately, the system is so

overwhelmed that the caseloads are very high and it is difficult to provide the specialized service that you know some clients require. Recommendations regarding lighter workloads and requests for more social workers have been exhaustively reported as a concern for many years. With smaller caseloads, workers would be able to provide more visits and phone calls and improve relationships with young people with FASD in care.

FASD practice standards for children in care of Alberta Children's Services were evaluated in a recent study (Badry, 2009) due to the estimate of 50% of children in care in Alberta having FASD. The research supported the case that specialization in the delivery of child welfare services is required for the population of those with FASD. Manitoba Child Welfare Authorities should create and implement FASD Practice Standards.

Recently, four FASD Specialists attached to each of the four child welfare authorities, were hired. Consultation to workers is available however, this is a very small part of their role and they can't possibly provide consultation to a whole authority. I would recommend FASD (and other special needs) Consultants or Specialists in each agency to provide consultation and specialized training to staff and management. This recommendation was also put forth in the Child Death Review 2006 (Schibler & Newton, 2006). Training needs to go beyond FASD 101 and enter into a more specialized training about how to care and plan for/with children in care with FASD and work with parents with FASD. With more knowledge and specialized training, workers will learn to assess, intervene, and plan in an FASD-friendly manner through the child's time in care and build a comprehensive care plan for transition. With this knowledge, better decisions

will be made regarding placements in care, school and other environments, more support will be given to care givers and it will mitigate secondary disabilities of FASD.

Talking to the Young Person with FASD about Family

One of the topics most anguished over by participants in this study was family. Every young person has been affected by their separation and abandonment of birth family. There seemed to be even more pain associated with the topic of their birth mothers. It is critical for workers and care providers to ensure that messages are sent to children and youth in care with FASD that explain what happened to them and why they are not with their family. I am talking about a special message to them regarding the fact that their mother used alcohol during pregnancy. It is important to let the young person know that their mother cared about them and did not do this intentionally to harm them and that it was absolutely not their fault. It is important for them to know that there will be challenges ahead because their brain is different/ damaged because of the alcohol and that care givers will be there through these challenges to help manage them. They need to know that there are many people with FASD that have happy and successful lives when they have the support they need. Like all children, they need to be told they are loved no matter what they do wrong. These messages will need to be repeated to them through the years to ensure they remember that they will be ok and they are worthy and loved.

A common theme surrounding family was also that birth families continued to struggle with addictions and other issues. Some young people will require additional support with accepting and dealing with the fact that their family is still unhealthy and

unable to be a support to them and have a relationship with them. This can be very upsetting for young people and again they need to be reminded that it is not their fault. One participant advised that he was reacquainted with his birth mother and had his hopes up too high and there was no one to help him deal with his feelings when the reunion did not go as well as he had hoped. Young people with FASD will require additional emotional supports if they encounter a reunion with their birth mother.

Some youth with FASD have a psychological family compiled of friends, support workers, staff in an organization or community resource. This should never be discouraged as a form of a family because for many youth, they don't have any biological family members in their life and their psychological family *is* their family.

Gradual and Supported Transition to Adulthood

As stated earlier, young people with FASD whether diagnosed or not identified, are at risk of transitioning to adulthood without the support and services they need to survive. It is hard to comprehend that a system that has cared for a child with a disability all their childhood, one day because they reach a certain chronological age, evicts them from their care without a safety net. Not only have these youth been abused and neglected, placed in substitute care and away from family, but they have struggled with the primary and secondary disabilities of FASD and don't have the luxury of the safety net of family as many of us do when we reach adulthood. In Canada, 93% of 18 year olds live with their parents, as do 57% of those between the ages 20 and 24, and 41 % of those aged 20-29 (Fuchs et al, 2008). Youth with FASD are not afforded the same opportunities in transitioning to adulthood with familial support as the general

population. Rutman and Hubberstey (2007) recommend that all youth in care need to have as gradual and extended a transition process to adulthood as youth in the general population. There is actually considerable recognition that all children in care need agency support beyond their 18th birthday and even more so for youth with FASD (Fuchs et al, 2007; Schibler & Newton, 2006).

Individuals with FASD are developmentally younger than their age, with strengths in some areas and limitations in others. They all require some services and supports after age 18 and deserve continued care from CFS in order to “practice and try on adulthood” and allow for some additional maturity to occur. Only youth with an I.Q. under 70 receive Adult Services in Manitoba and guaranteed support in adulthood. The Child and Youth Officer of BC (2006) recommended expansion of requirements of Community Living by recognizing adaptive functioning as an equally important indicator of the need for lifelong community services. I would echo this recommendation. Experts suggest that agency care needs to be replaced with a structured environment that includes the support of a one on one advocate or mentor (Gough & Fuchs, 2008). Many young people with FASD have IQ’s above 70 are therefore are not eligible for services yet they pose as much or more of a risk being alone than does someone without FASD with an IQ under 70. Gough and Fuchs (2008) found that only 33% of youth with FASD profiled, received transition planning status and received an extension in care for up to one year. Only one of these youth had their care extended until age 21. Only 11 % of these youth had files that included a comprehensive plan for transition out of care. Therefore, extensions in care should be granted for all youth with FASD in care and those that are

suspected of having FASD. An assessment of their adaptive functioning should occur and interventions and supports be implemented according to their needs.

Life skills need to be assessed and hands on training occur in order to prepare the person for some independence later in life. Practicing work is also recommended in the transition to “try on” what it is like to have a job and become a reliable and contributing citizen. Adults with FASD can gain a feeling of competence from working which is good for their self-esteem and can also combat those powerful secondary disabilities. Young adults also need help navigating other systems that they might be involved with, i.e. Employment and Income Assistance, Health and Justice. The Child and Youth Officer of BC (2006) recommended the development of a cross-agency plan for youth transitioning to adult system involving all the systems involved. Connection to resources in the community that are FASD-friendly is another task that needs to occur in the transition. New freedoms come along with turning age 18, for example, alcohol is now legal for these young people. Not a better time to have a safety net, as when you get to legally use alcohol and are easily influenced to do so. Continued education and role playing about safety and risk is a critical piece at transition time. When I asked the two youngest participants (ages 16 and 18) what it is they need to become independent safely and successfully, they both said, “I don’t know”. Often with individuals with FASD, looking/planning ahead is not possible if the executive functioning of the brain is impaired. Looking into the past is difficult if you have memory problems. Most seem to manage best in the present. Independence is also an abstract concept and if you are a concrete thinker, this would be difficult to comprehend. Our eldest participant (age 28) told me that he did not understand when he was transitioning to adulthood and he

attended meetings and was not sure about what people were planning for him. He was reluctant to go along with what professionals were planning because he did not know what it would mean for him. When asked about what he would have needed in order to transition to adulthood, he said that he would need support in every area of his life.

Each participant felt that they had supervision, support and services in line with what their needs were at the time of the interviews. The professionals and care givers working with them had recognized that they needed additional support due to their disability and mental health issues and the adults in the study had been transitioned appropriately to Adult Services. Many young people with FASD are not transitioned appropriately and unfortunately lead high risk lives as a result.

Mitigating Secondary Disabilities

The secondary disabilities reported in this study were striking. All of the participants struggled with mental health, school disruption, trouble with the law and confinement. All five participants had additional mental health diagnoses and had taken psychotropic medication in the past or currently were medicated. A few encountered serious problems with alcohol and drugs, both female participants, to the point that their lives were placed at risk. None of the participants were living independently with the most independent participant having 9 hours of staffing per day. What does this tell us?

This tells us that the environments (people and places) that these young people have lived and learned in over the years have had trouble understanding FASD and how the disability impacts each individual young person. This tells us that the myriad of

systems working with young people with FASD are not meeting their needs and making accommodations for them as people with a disability. These systems are: child welfare, mental health, justice, and education. This also tells us of the power of the primary disability of brain impairment and the enormity of challenges for these young people in daily living. What should we do about it?

Prevention of Secondary Disabilities for New Children in Care

Children coming into care who are flagged as possibly alcohol affected need to be assessed for FASD and intervened with accordingly. We know that with a diagnosis under FASD, the young person will be identified as someone who requires extra support and there is more understanding of the young person's challenges. They should then be placed in specialized placements and care givers should be educated and skilled in FASD and use appropriate strategies. The plan for their transition should be gradual, comprehensive and provide support at all levels. With this level of support and services and understanding people and places, secondary disabilities should be mitigated in this group of young people.

Interventions with Youth in Care with FASD

Young people in care with FASD, who already present with secondary disabilities, require people, places and plans that are FASD-friendly. The recommendations for care givers talked about earlier can be transferred to care givers and staff in institutions and treatment centers and the CFS worker recommendations can be transferred to other case managers of young people with FASD. Professionals working

with individuals with FASD need to be educated about the disability, make a paradigm shift, and work differently with these young people. Interventions need to be formulated around the needs of the person stemming from the affected brain domains. FASD needs to be “on the table” when considering different interventions, for example, medicating for a mental health issue, supporting the young person in court or receiving addictions treatment. These interventions will look very different for young people with FASD than someone with typical brain. Advocacy at this time is critical and setting the young person up with other professionals that are FASD-friendly is important to mitigating secondary disabilities or at least not adding to them. Opie (2007) reports that with a strong relationship/ attachment to at least one healthy and available adult, young people with FASD will be less likely to get into difficulties. They have someone to talk to and someone to guide them into healthy activities (Opie, 2007). With all these secondary disabilities, the risk elevates and the need for more supervision and support is necessary.

Culturally Appropriate Services

Due to the over-representation of Aboriginal youth in care and the overwhelming number of Aboriginal young people in care with FASD, it is recommended that they be afforded culturally appropriate service through their journeys in care. The Child and Youth Officer of BC (2006) found in their study on youth with FASD aging out of care, that more than half of the youth who age out of care are Aboriginal, a significant number of them having FASD. The findings suggest that young Aboriginal adults with FASD respond well to services that are culturally appropriate, that are provided by Aboriginal people and that connected the youth with their community. In my work with Aboriginal

children and youth over the years, there have been many who have responded to traditional forms of practice and there have been some that chose alternate forms of practice, healing, traditions and spiritualities. The key is to recognize the overwhelming number of Aboriginal young people with FASD in care and to ensure that each young person is provided the opportunity to have culturally appropriate services in their journeys through care and through to their transition to adulthood.

Conclusion

In summary, the co-formulated recommendations based on the analysis of the data, personal experiences, previous research and participant suggestions included a myriad of aspects. In order to improve the care of children and youth with FASD, we the system need to ask those with the lived experience and heed their advice in making the child welfare, justice, mental health and educational systems more FASD-friendly. Hopefully, the current study has provided a first look from the voices of the experts about what might improve care for young people with FASD. At a time when child welfare is beginning to admit that we are not providing adequate care to a certain group of kids in care, this research is timely. Other similar research is underway in this province and it has become evident that the subject of FASD is finally getting some of the attention it deserves. We need to develop a comprehensive plan in each system regarding how we are going to work differently with this population of people. We need to keep shining the light on FASD and continue listening to the voices of those who live with the disability in order to promote successful outcomes for all individuals with FASD.

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Appendix A
Call for Participants

Are you a Current or Former Youth in Care living with FASD who is between the ages of 16-30, who would like to share your experiences?

The purpose of this project is to hear about the experiences and needs of youth with FASD in care and to make recommendations to the child welfare, justice, education and mental health systems about how to better take care of youth with FASD.

My belief about where to get the best information about this topic is from the youth themselves, the EXPERTS on living in care. This project is an opportunity for those youth who want people to know about their experience to tell their story in an interview.

Your stories are important and your input is needed! If you are interested in participating, please call Allison at the following confidential phone number xxx-xxxx.

*All participants providing an interview will be paid \$20.00 for your time.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba.

Appendix B Verbal Script for Participant

Let me tell you a bit about this research...

I am a social work student at the University of Manitoba. I am working on my thesis, which is a huge paper that I have to finish to get my degree. I have to pick a research topic, ask people questions in an interview and then write up what we found out about the topic. I chose to research youth with FASD who are in care (or were in care) because I wanted to hear about what it was like for them. I also want to know if they have any ideas about how to make it better.

Let me tell you about a bit about me...

Over the past 18 years, I have been working as a youth care worker and now a social worker with teenagers and their families. I have worked at Marymount, the Mobile Crisis Team, Macdonald Youth Services, the Manitoba Youth Center and Child & Family Services where I work now. I work as an Intake worker at the office on Portage Avenue. We call our agency ANCR. I am currently off work on a leave until January 2010.

Over the years, I have noticed that there are many kids in care that have FASD. Some have a diagnosis and some do not. I know that sometimes life is difficult for kids in care, sometimes even harder for kids with FASD. I think that a lot of people do not understand what FASD is and how people with FASD might think and behave. I know that I did not understand FASD when I first started helping kids. I think I made a lot of mistakes.

I need help from youth with FASD because I think they have a lot of experience and ideas. I think that if they told their story about living in care, people would listen and understand youth in care better. I want to work together with youth with FASD to find some solutions to make it better in care.

This is what we would do...

We would talk about the research and see if you are interested in participating. If you were interested, we would go over a consent form in person that explains the research, your participation and your rights in the research. You need to bring an advocate (helper)/ your guardian/parent to help you with this form and sign their consent for you to participate. You, your helper and myself, can all sign this form together. If you ever want to leave the research project, you can and this will not be a problem. This would probably take no more than a half an hour.

The next step is you and I would meet at a place (home, office, community) that we both agree upon and I would interview you about living in care. I would tape record the interview with a small digital recorder. I will ask you questions about your experience in care, about living with FASD, what your support needs are and about what recommendations you might have for people working with you. The interview will be approximately one to two hours. After this, your part is finished, except if you have questions or you want to know the outcome of the research. You can call me anytime after the research at the same number on the poster you saw. You will receive \$20.00 for your participation in the interview and my appreciation for your contribution to the research. I will then take the information and look for themes in the interviews among

participants and then I will write a paper about the findings. You have the option of receiving a summary of the final paper when it is finished.

I believe that youth with FASD are the experts, the ones with a lot of the information about what we need to make things better. What do you think of this research? Do you think you would be interested? This is a lot of information. If you need to think about this and want to talk about this again, you can call me at xxx-xxxx.

Appendix C Verbal Script for Guardian

Let me tell you a bit about this research...

I am a social work student at the University of Manitoba. I am working on my thesis and when it is complete I will receive my MSW degree. I have chosen to research youth with FASD who are in care (or were in care) because I am interested in finding out what the experience was like for them. I want to know what their support needs are and also want to know if they have any ideas about how to make it better in care so that we can together put forth some recommendations for professionals.

Let me tell you about a bit about me...

Over the past 18 years, I have been working as a youth care worker and now a social worker with children, teenagers and their families. I have worked at Marymount, the Mobile Crisis Team, Macdonald Youth Services, the Manitoba Youth Center and Child & Family Services where I work now. I work as an Intake worker at ANCR, which is the intake office. I am currently off work on a leave until January 2010.

Over the years, I have noticed that there are many kids in care that have FASD. Some have a diagnosis and some do not. I know that sometimes life is difficult for kids in care, sometimes even harder for kids with FASD. I think that a lot of people do not understand what FASD is and how people with FASD might think and behave. I know that I did not understand FASD when I first started helping kids. I think I made a lot of mistakes. This is what brought me to my current research topic.

I need help from youth with FASD because I think they have a lot of experience and ideas. I think that if they told their story about living in care, people would listen and understand youth in care better. Traditionally, we have left their voices out of the equation and I want to be able to give voice to the experts. I want to work together with youth with FASD to find some solutions to make it better in care.

This is what would be expected of the participant...

We would talk about the research and see if s/he is interested in participating. If so, we would go over the consent form in person with you. The consent form explains the research, the expectations of her/his participation and his/her rights in the research. The participant, I and the guardian will sign the consent form together, which should not take more than half an hour to complete.

The next step is the participant and I would meet at a place (home, office, community) that we both agree upon and I would interview her/him about living in care. I would tape record the interview with a small digital recorder. I will ask questions about the experience of living in care, about living with FASD, what his/her support needs are and about what recommendations s/he might have for professionals/family members. The interview will take approximately one to two hours. After this, the participant's part is finished, except if he/she has questions or wants to know the outcome of the research. S/he can call me anytime after the research at the same number on the recruitment poster. Each participant will receive \$20.00 for their participation in the interview and my appreciation for their contribution to the research. I will then take the information, analyze the data by looking for themes in the interviews among participants and then I

will write the final thesis about the findings. Participants and guardians have the option of receiving a summary of the research once the final paper is finished.

I believe that youth with FASD are the experts, the ones with a lot of the information about what we need to make things better. What do you think of this research and about your child being involved in the project?

Appendix D

Email Script for Research

“The Experiences and Needs of Young People with FASD: Silenced Voices from Youth in Care”.

The purpose of this MSW thesis is to explore the experiences of young people with FASD in care and examine their support needs from their perspective. I will be interviewing 5 young people between the ages of 16-30 about their experiences in care. The categories in my interview guide are: history in care, living with FASD, support needs and recommendations for caregivers/professionals. I am utilizing an Anti-Oppressive research framework, with youth with FASD being considered the “experts”. I am not asking for information from caregivers or professionals in this thesis project, as I want to focus on the youth’s perspective. This is not to say that caregivers and professionals would not contribute valuable information in this area, instead, I want the light to shine on the youth.

This research is an attempt to hear the voices that are often silenced in this area. I would like the youth to be a part of offering solutions for change in the care that they receive. By “in care” I not only mean a foster home or group home setting, but also when children in care have been admitted to mental health facilities (CSU, PY1, PY2) and have become incarcerated (MYC, Headingly). I am also adding a piece regarding learning and school experience so we do not forget the issues in the education system for these folks. So, I am hoping to gather information regarding child welfare, justice, education and mental health systems.

The research has received acceptance from Ethics at the University of Manitoba and I am currently in the recruiting of participant’s stage of the research. Each participant will be paid \$20.00 for the (approx. 1 hour) interview they provide and this will be the end of their involvement in the study. Breaks will be utilized if needed. I have prepared consent forms for guardians and advocates and assent forms for youth with FASD. I will provide a summary at the end of the research to the participant and guardian, if desired.

For the purposes of this research, the youth will have to be somewhat aware that they are alcohol affected in order to speak about living with FASD. However, they do not need a formal diagnosis within the FASD spectrum. The youth will have to be able to speak to their experience in care and will need to be at a developmental level in which this type of interview is viable. This will be determined by the individual, the guardian/advocate and the researcher. The participant will be told that the researcher also works for Child and Family Services (ANCR). Although the researcher works for Child and Family, the youth will be told that the information provided by the participant will not have any influence on the service provided to them in any area and the researcher has compiled this research in order to make things better for youth with FASD. The location of the interview is negotiable with the most comfortable setting for the participant being preferred. The researcher will ensure that the participant is transitioned

back to an appropriate caregiver/professional at the end of the interview in case debriefing is needed.

If you have further inquiries about this research, feel free to call me at xxx-xxxx or my MSW Thesis Advisor Dr. Susan Strega, **collect** at the University of Victoria at 1-250-721-8333.

Thank you for your interest in this important research.

Allison Chatterley-Gonzalez, B.A. Adv., M.S.W. Cand.

Appendix E
Assent Form for Participant

Research Project Title:

“The Experiences of Young People with Fetal Alcohol Spectrum Disorder: Silenced Voices From Youth In Care”.

Researcher:

Allison Chatterley-Gonzalez, Graduate Student

Research Supervisor:

Dr. Susan Strega, Professor- University of Victoria
1-250-721-8333

This research project explores the experiences of youth with FASD who are or have been in care. You will be asked in an interview about your personal experiences and opinions about living with FASD and being in care. This project is a Master’s Thesis which I am conducting as a student researcher. I am a Graduate student from the University of Manitoba working under the supervision of Dr. Susan Strega.

The information gathered in the study will be confidential. Interview results will be kept in a locked filing cabinet, in a locked room and only the student researcher and her supervisor will know the participant’s names. Anonymity will be guarded as much as possible and your name will not appear on any documents. Participation in this study is voluntary and you can choose whether or not to answer a question and you can withdraw from the interview or the study at anytime, without giving any reasons.

The one to one interview will be between one and two hours in length and will explore your experiences in care, living with FASD, what type of supports you think are needed and your opinion about recommendations for professionals working with youth with FASD. The interview will be recorded with a small digital recorder and the recording will be erased after the interview is transcribed. You will have the option of reviewing the transcript and changing any of the information provided. If you do not want to be tape recorded, you can refuse to be recorded and I would take notes instead. You will be paid \$20.00 for participating in the interview.

I need to let you know that I am an Intake Social Worker with All Nations Child and Family Services as well as a student at the University of Manitoba. Whether you choose to go forward with participating in this study or not, this will have no relation to the services provided to you by CFS in any area of your life, and no other professionals will have access to the information provided in the study. I also need to let you know that if at any time I hear about a child/youth being neglected or abused or that someone is threatening to hurt someone or themselves, I have to report this information to the authorities. Due to the nature of the questions in the interview, you might have some

feelings that may come up and might cause some stress. If this occurs, I need you to tell me so that I can help you. We can debrief and return to the interview, we can end the interview, I can refer you to some other resources afterwards and/or we can advise your caregiver after the interview about the distress in order to ensure continued support.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns about this project, you can contact the Human Ethics Secretariat Maggie Bowman at 474-7122. As well, Dr. Susan Strega is my Thesis Advisor and she can be reached at 1-250-721-8333, by calling **collect** to the University of Victoria. If you or your caregivers wish to receive a summary of the research you can do so by indicating below (Yes or No) and also please indicate the mechanism by which you would like the summary sent (email or surface mail). The summary will be available to you after the final thesis is complete, which is expected to be March 2010.

I would like to receive a summary of the research: YES or NO via Email or
Surface Mail

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

I agree to participate in the research.

YES or NO

Appendix F
Consent Form for Legal Guardian of Participant

Research Project Title:

“The Experiences of Young People with Fetal Alcohol Spectrum Disorder: Silenced Voices From Youth In Care”.

Researcher:

Allison Chatterley-Gonzalez, Graduate Student

Research Supervisor:

Dr. Susan Strega, Professor- University of Victoria

This research project explores the experiences of youth with FASD who are or have been in care. Research participants will be asked in an interview about their personal experiences and opinions about living with FASD and being in care. This project is a Master’s Thesis, being conducted by student researcher Allison Chatterley-Gonzalez who is a Graduate student from the University of Manitoba working under the supervision of Dr. Susan Strega.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what the participant’s participation will involve. If you would like more detail about something mentioned here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The information gathered in the study will be confidential. Interview results will be kept in a locked filing cabinet, in a locked room and only the student researcher and her supervisor will know the participant’s names. Anonymity will be guarded as much as possible and participant’s names will not appear on any documents. Participation in this study is voluntary and participant’s can choose whether to answer a question or not and can withdraw from the interview or the study at anytime, without giving any reasons.

The one to one interview will be between one and two hours in length and will explore the participant’s experiences in care, living with FASD, what type of supports are needed and recommendations for professionals working with youth with FASD. The interview will be recorded with a small digital recorder and the recording will be destroyed after the interview is transcribed. Participant’s have the option of reviewing the transcript and changing any of the information provided. If the participant does not want to be tape recorded, they can refuse to be recorded and the student researcher would take notes instead. Each participant will be paid \$20.00 for participating in the interview. The \$20.00 will be paid to the participant even if they decide to withdraw from the project at any time, for any reason.

The student researcher is an Intake Social Worker with All Nations Child and Family Services as well as a student at the University of Manitoba. Whether the participant chooses to go forward with participating in this study or not, this will have no relation to the services provided to the participant in any area of their life, and no other professionals will have access to the information provided in the study. If at any time the student researcher hears about a child/youth being neglected or abused or if she hears about someone threatening to hurt someone or themselves, the student researcher has to report this information to police or child welfare authorities. Due to the nature of the questions, the participant might have some feelings that may come up that might cause some stress. If this occurs during the research, the participant is expected to advise the researcher so that appropriate intervention can take place. Debriefing and returning to the interview, terminating the interview, referral to other resources or advising caregivers after the interview in order to ensure continued support are some of the intervention options.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns about this project, you can contact the Human Ethics Secretariat Maggie Bowman at 474-7122. As well, Dr. Susan Strega is my Thesis Advisor and she can be reached at 1-250-721-8333, by calling **collect** to the University of Victoria. If you wish to receive a summary of the research you can do so by indicating below (Yes or No) and also please indicate the mechanism by which you would like the summary sent (email or surface mail). The summary will be available to you after the final thesis is complete, which is expected to be March 2010.

I would like to receive a summary of the research: YES or NO via Email or Surface Mail

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's/client's participation in this research project, as well as your belief that the participant has understood the assent form read to them and finally, that you consent to your child/client participating as a subject. In no way does this waive the participant's legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. The participant is free to withdraw from the study at any time, and/or refrain from answering any questions s/he prefers to omit, without prejudice or consequence. Her/his continued participation should be as informed as her/his initial consent, so the participant should feel free to ask for clarification or new information throughout his/her participation.

Legal Guardian

Date: _____

Allison Chatterley-Gonzalez
Principal Researcher

Date: _____

Appendix G
Consent Form for Independent Adult

Research Project Title:

“The Experiences of Young People with Fetal Alcohol Spectrum Disorder: Silenced Voices From Youth In Care”.

Researcher:

Allison Chatterley-Gonzalez, Graduate Student

Research Supervisor:

Dr. Susan Strega, Professor- University of Victoria

This research project explores the experiences of youth/young adults with FASD who are or have been in care. Research participants will be asked in an interview about their personal experiences and opinions about living with FASD and being in care. This project is a Master’s Thesis, being conducted by student researcher Allison Chatterley-Gonzalez who is a Graduate student from the University of Manitoba working under the supervision of Dr. Susan Strega.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The information gathered in the study will be confidential. Interview results will be kept in a locked filing cabinet, in a locked room and only the student researcher and her supervisor will know the participant’s names. Anonymity will be guarded as much as possible and participant’s names will not appear on any documents. Participation in this study is voluntary and participant’s can choose to answer a question or not and can withdraw from the interview or the study at anytime, without giving any reasons.

The one to one interview will be between one and two hours in length and will explore the participant’s experiences in care, living with FASD, what type of supports are needed and recommendations for professionals working with youth with FASD. The interview will be recorded with a small digital recorder and the recording will be destroyed after the interview is transcribed. Participant’s have the option of reviewing the transcript and changing any of the information provided. If the participant does not want to be tape recorded, they can refuse to be recorded and the student researcher would take notes instead. Each participant will be paid \$20.00 for participating in the interview. The \$20.00 will be paid to the participant even if they decide to withdraw from the project at any time, for any reason.

The student researcher is an Intake Social Worker with All Nations Child and Family Services as well as a student at the University of Manitoba. Whether the participant chooses to go forward with participating in this study or not, this will have no relation to the services provided to the participant in any area of their life, and no other professionals will have access to the information provided in the study. If at any time the student researcher hears about a child/youth being neglected or abused or if she hears about someone threatening to hurt someone or themselves, the student researcher has to report this information to police or child welfare authorities. Due to the nature of the questions, the participant might have some feelings that may come up and might cause some stress. If this occurs during the research, the participant is expected to advise the researcher so that appropriate intervention can take place. Debriefing and returning to the interview, terminating the interview, referral to other resources or advising caregivers after the interview in order to ensure continued support are some of the intervention options.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns about this project, you can contact the Human Ethics Secretariat Maggie Bowman at 474-7122. As well, Dr. Susan Strega is my Thesis Advisor and she can be reached at 1-250-721-8333, by calling **collect** to the University of Victoria. If you wish to receive a summary of the research you can do so by indicating below (Yes or No) and also please indicate the mechanism by which you would like the summary sent (email or surface mail). The summary will be available to you after the final thesis is complete, which is expected to be March 2010.

I would like to receive a summary of the research: YES or NO via Email or Surface Mail

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

_____ Date: _____
Research Participant

_____ Date: _____
Advocate

_____ Date: _____
Allison Chatterley-Gonzalez

Appendix H Interview Guide

Demographic Information and Building Rapport:

- Tell me a bit about yourself- your age/who you live with.
- What are your current living arrangements and the relationship to this placement?
- Do you attend school/work/have interests/take part in recreational activities?
- As you know, this interview is about your experiences in care and also about having FASD...so let's talk about your history in care.

History in Care:

- How old were you when you came into care and how long have you been in care?
- What was the reason that you came into care?
- Tell me the number of placements you have had and the types of placements.
- Have you ever been in jail (MYC)/in a crisis unit (CSU) or psychiatric facility (PY1)? Why were you there? And for how long?
- Tell me about this experience. How were you cared for by the staff?
- Tell me about your experience with school and with teachers.
- Tell me where your best placement was and the reason it was the best. What did your caregivers do that made it a good place to be?
- Tell me about your current contact with family and your relationship with them.
- How are you cared for/supported by your family?
- Tell me your wish about family.
- What is the long term plan for you in care? How do you feel about this plan?

Living with FASD:

- How old were you when you learned about FASD?
- Who explained FASD to you and how?
- Do you have a diagnosis of FASD? How old were you when diagnosed and what was that like for you?
- What does FASD feel like?
- What things are hard/easy for you to manage?
- Tell me what some of your strengths are/what you are good at/proud of?
- Tell me- Is learning hard for you? What makes learning easier?
- What works for you? What doesn't work?
- Do your caregivers/social worker/family understand how FASD affects you?
- Who is your biggest advocate/helper? What do they do that helps?
- Tell me about your relationships with peers/friends.

- Have you had trouble with the law? Addictions? Mental health issues? School?
- Tell me about your goals/dreams in life.

Support Needs:

- What would help you to manage home, school and the community better?
- What type of advocacy have you had and how was it helpful?
- What kinds of support/services would help you in care?
- Have you had a say in decision making regarding planning?
- Tell me what you need in order to transition to independent living safely and successfully.
- Tell me what the barriers/challenges/achievements have been in transitioning to adulthood.

Recommendations for Professionals:

- Tell me about your relationship with your caregivers/social worker.
- Tell me what an ideal caregiver/social worker would be like. What would you need from them?
- What could they do with placements to make them better?
- If you could change anything about being in care, what would it be?
- What advice would you give to staff/caregivers/social workers/teachers in caring for/working with youth with FASD in care?
- What advice would you give to other youth with FASD coming into care for the first time?
- Do you have any other ideas about what would make it better in care for youth with FASD?