

SUPPORTS TO IMPROVE THE LIVES OF ADULTS WITH FASD:
AN ETHNOGRAPHIC STUDY OF A MENTORSHIP PROGRAM

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Abstract

This ethnographical study provides insight into the daily lives of adults with Fetal Alcohol Spectrum Disorder (FASD) and demonstrates how mentorship increases their quality of life. FASD is a life-long disability that diminishes a person's cognitive and adaptive functioning. In this study, adults with FASD and their mentors were interviewed at the CUMFI (Central Urban Métis Federation Inc.) Wellness Centre, a mentorship program for individuals with cognitive disabilities in Saskatoon, Saskatchewan to determine how effective supports were and how to improve the supports. This research was approached through critical ethnography and the result is a call for social change to help individuals with FASD.

The CUMFI Wellness Centre is an effective mentorship model that could be used to design other mentorship programs for adults with FASD across the country. In this study, it was determined that the adults with FASD involved in the mentorship program at the CUMFI Wellness Centre had increased self-esteem and a better quality of life.

Mentorship helps adults with FASD to find housing, buy groceries, receive community supports and maintain a healthy lifestyle which will help them function better in society. Support and mentorship provides safeguards to decrease the likelihood of adults with FASD ending up on the streets, in jails, hospitals and treatment centers. We must respond to the needs of these individuals and their families and provide supports for them. It is ethical that we do so as these individuals were not responsible for their cognitive disability from the prenatal alcohol to which they were exposed. It is practical and cost-effective to assist this population so that they can healthy and productive members of our society.

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Chapter I: Introduction

Adults who are affected by Fetal Alcohol Spectrum Disorder (FASD) face daily struggles caused by neurological impairment due to their exposure to alcohol in the womb. In order for them to have the best quality of life possible, long-term supports are needed. It is essential that society recognizes the long-range and lasting impact of prenatal alcohol exposure on individuals.

To begin with, some background information on FASD and the terminology is needed. When a pregnant woman drinks, alcohol is a teratogen (poison) that interferes with the normal development of the unborn child. We are most concerned about the damage to the central nervous system for individuals with FASD.

Fetal Alcohol Spectrum Disorder (FASD) is not a diagnostic term but rather a general term that includes individuals who have Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Neurodevelopmental Disorder (ARND) and Alcohol-Related Birth Defects (ARBD). A diagnosis under the FASD spectrum consists of four domains: 1) alcohol exposure during pregnancy, 2) growth retardation, 3) facial phenotype and 4) central nervous system dysfunction or damage.

It is important to realize that FASD covers a wide spectrum from lower to higher severity of how a person is affected. When and how much the mother drank while pregnant, the genetic makeup and resilience of the mother and the developing fetus as well as other factors such as maternal nutrition, medical care and the addition of other teratogens affect the individual, with the extent of resulting brain damage dependent on those variables (PHAC, 2009).

I was brought to an awareness of the needs of young adults with FASD as a special educator. I have worked in rural, urban and First Nations schools for over fifteen years and have been exposed to the unique challenges of my students with FASD. As I watched my students graduate from high school, I became concerned that services to continue to support these young adults were either not available or lacking. Some of my students in foster care placements were on their own once they turned eighteen but were not ready for this independence. It is difficult for any young person to transition from high school to the adult world. I felt it is unrealistic to expect individuals with FASD to make this transition without proper supports. This motivated me to learn about and advocate for long-term supports for adults with FASD.

Assistance in the areas of housing, employment and healthy living skills can make an enormous difference in the lives of adults with FASD. Support services are being delivered to this population but more research is needed as to the effectiveness of these supports. Support services, such as mentorship, can ensure that adults with FASD have an improved quality of life. These services can help to prevent secondary disabilities from developing in individuals with FASD such as mental health disorders, alcohol and drug addictions and/or trouble with the law. By providing support, society will save costs of dealing with secondary disabilities and individuals with FASD will experience greater potential and improved self-esteem.

I will approach my research from a critical ethnography method, where I will advocate for a group of people and call for social change to help individuals with FASD. Thomas (1993) describes critical ethnography as a type of research in which the authors advocate for the rights of a marginalized group in society. Adults with a cognitive

disability such as FASD are marginalized and often have to struggle for things that the dominant society takes for granted. The intention of my research will be to put forward the needs of adults with FASD so that supports for this population can be extended and improved.

There are three main objectives of this thesis. The first objective is, through an ethnographic study to better understand the lives of adults with FASD. This research will uncover and report the experiences in the daily lives of adults who live with the effects of fetal alcohol exposure. It is important that their experiences be understood so that we can assist them in achieving a better quality of life. As researcher, I will conduct interviews and observations with these adults in order to gain insight into their common experiences.

The second objective for my research is to report upon the impact of the CUMFI Wellness Centre (Central Urban Métis Federation Inc.) on adults with FASD. The CUMFI Wellness Centre provides a mentorship program for older youth and adults with cognitive disabilities including adults with FASD. By interviewing the adults with FASD receiving services at the CUMFI Wellness Centre and the staff, I will determine what is working for these adults and also in which areas they are still struggling. By including the perspectives of both the individuals with fetal alcohol damage and their support staff, the study will provide great depth and insight which will help improve the services given to adults with FASD.

The final objective of the research is to provide recommendations on how to best support adults with FASD. These recommendations will evolve from the study and will be able to guide the future development of support programs for this population. This

study on a mentorship program for adults with FASD can be used as a tool for social change.

In my study, the adults with FASD exposed their struggles, their needs and their hopes. Their mentors completed the picture by describing the ways in which they try to support these adults in their daily lives.

Chapter II: Literature Review

Introduction

This research will report on the perspectives of adults with Fetal Alcohol Spectrum Disorder (FASD) on the supports they are receiving at a mentorship program in Saskatoon, Saskatchewan. The viewpoint of support staff at the program will also be included in the study. This chapter will explain the prevalence as well as the primary and secondary disabilities of FASD. An overview of the societal cost of FASD will be covered as well as some support programs that are attempting to address the societal issue of FASD in Canada.

There is a significant amount of research that demonstrates the need for supports for adults with FASD (Streissguth, et al., 2004; Caley et al., 2006 & Grant et al., 2004; Harriman, 2007; Clark, 2003). Grant et al (2005) state:

Clinical reports indicate that a poor quality of life is a grim reality for most adults with FASD because their broad spectrum neurobehavioral deficits continue to impair functioning across the lifespan and because access to services that might ameliorate their circumstances is either inconsistent or uncoordinated (p.33).

“The low level of societal protection and support given to people with FAS and FAE and their families is unacceptable and further compromises their lives” (Streissguth, Barr, Kogan & Bookstein, 1997, p. 38). Lack of adequate support for individuals with FASD can result in school failure, family stress, trouble with the law and difficulty with daily living activities and keeping a job (Wright, Dinning, Podruski, & Fox, 2004). This study shows how mentorship can make a difference to the lives of adults with FASD by reducing these possible negative outcomes.

Prevalence

The leading known cause of developmental disability in Canada is Fetal Alcohol Spectrum Disorder (Poole, 2008). The most commonly used prevalence for FASD is at least 9.1 per 1000 live births (Sampson, et al., 1997). This is almost 1 in 100 births and is considered to be an underestimate due to the difficulty with diagnosis. In a study done in an isolated Aboriginal community in British Columbia, the prevalence rate for FAS was 190 per 1000 live births (Robinson, Conry & Conry, 1987). Another study in a First Nations community in Manitoba estimates a prevalence of FAS of 55-101 per 1000 live births (Square, 1997).

It is difficult to estimate the prevalence and incidence of FASD because it is difficult to diagnose and there is evidence that the majority of incidences of FASD are undiagnosed (Sokol, Delaney-Black, & Nordstrom, 2003). A mother's confirmation that she drank during pregnancy is needed in diagnosing pFAS, ARND and ARBD and is only not needed in diagnosing FAS when enough criteria are present. It can be difficult to get a mother's confirmation due to the shame and stigma attached in addition to the fact that some adopted children do not have contact with their birth mother. Many physicians are not trained in diagnosing FASD. A multi-disciplinary team approach is best including a nurse or social worker, trained physician, psychologist, occupational therapist and speech-language pathologist.

It is difficult to get accurate Canadian statistics as it is not yet mandatory to report a diagnosis of FASD. Unfortunately, the lack of accurate statistics makes it difficult to plan and designate funds for the necessary supports and services that are needed for

individuals with FASD and their families. None the less, statistics show that FASD is a significant problem and must be addressed.

An Invisible Disability

FASD is often called an “invisible disability” as it often goes undiagnosed and unnoticed in adolescents and adults (Malbin, 2008). Individuals with FASD can appear like they do not need any help when they do. Only a small percentage of individuals show the characteristic facial abnormalities such as short palpebral fissures (eye slits) that can be used to help with diagnosis. Many individuals with FASD do not have these identifiable facial anomalies as they had to have been exposed to high levels of alcohol at the time their facial features were developing. In addition, these facial features are less recognizable with age making accurate diagnosis more difficult with older individuals (Chudley et al., 2005).

Individuals with FASD often use sophisticated language but lack comprehension. This leads to unrealistic expectations for their behavior that may result in ridicule, blame and social stigma (Conry & Fast, 2000). In schools, at work and in court, expectations are often placed on individuals with FASD that are not reasonable and set these individuals up for negative outcomes.

Individuals with FASD can have low to above-average IQs. Unfortunately adults with normal to above-average IQ often have difficulty qualifying for special educational and vocational supports even though they have clear deficits in complex attention, verbal learning and executive function (Kerns, Don, Mateer & Streissguth, 1997). This is extremely problematic as it leads to unrealistic expectations of the individual who often faces school and/or employment failure.

Primary Disabilities

Primary disabilities are disabilities that an individual is born with (Streissguth, 1997). Individuals with FASD have primary disabilities caused by brain damage from exposure to prenatal alcohol. This primary neurobehavioral damage can impact cognitive, physical, behavioral or sensory functioning (FASD Support Network of Saskatchewan, 2007). In 2006, Merrick, Merrick, Morad & Kandel stated that:

Prenatal alcohol exposure leads to permanent and life-long damage which impair both the social and occupational future of the person exposed with a need for life-long assistance in order for that person to function at an optimal level (p. 211).

Primary disabilities of FASD include neuropsychological impairments in executive functioning, memory, attention, visual-spatial abilities, planning, processing speed and language and motor delays (Rasmussen & Wyper, 2007). The effects of the brain damage of FASD show up in the behaviors of the individual. There are ten domains of functioning that can be impaired by prenatal alcohol exposure (Lang, 2006), and can cause a lot of misunderstandings to parents, teachers and professionals who work with the individual. The ten domains that are damaged are as follows: achievement, adaptive behavior, attention, cognition, executive functioning, language, memory, motor skills, sensory/soft neurological and social communication.

This means that individuals with FASD can struggle with reading, math and written language. They may have difficulty with attention and concentration. Their ability to comprehend language and remember information can be impaired. They often struggle with decision making, learning from consequences and self-control. Concepts like managing time and money can be difficult for them. They may also have sensory

and motor impairments that can affect their daily life. Finally their ability to read and understand social cues can be diminished. These are some examples of the effects of the impairment to their ability to function.

Individuals with FASD have a gap in their chronological age and their actual developmental level that creates difficulty in their functioning and in how they are perceived (Malbin, 1999/2008). The transition for adolescent to adulthood is especially difficult for adults with FASD who may be expected to drive a car, hold down a job and manage money. The reality is that they may not be able to do these things.

Secondary Disabilities

Secondary disabilities are not present from birth but develop from primary disabilities and lack of intervention. Interventions for individuals with FASD prevent the development of secondary disabilities (Caley, Shipkey, Winkelmena, Dunlap, & Rivera, 2006). Secondary disabilities for individuals with FASD are mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual behavior and drug problems (Streissguth, 1997). Support programs like the CUMFI mentorship program for adults with FASD can help manage and prevent secondary disabilities. For example, an adult with custody issues can be helped by a mentor who advocates for his/her needs. Another adult may be prevented from getting into trouble with the law by the supports offered.

Adults with Fetal Alcohol Spectrum Disorder experience many difficulties in daily life. They are expected to function as self-supporting adults in society but this expectation is often unrealistic and sets them up for failure. Some adults with FASD are

not able to live independently and rely on support from their parents, relatives or agencies in the form of housing and assistance in daily living. This can cause a great deal of stress on both the individual with FASD and their caregiver. In Streissguth's study on secondary disabilities, 80% of people with FASD over the age of 21 were in dependent living situations (1997). Adults with FASD may need support in these areas: (a) homelessness, (b) finances, (c) health, (d) mental health, (e) addictions, (f) employment, and (g) legal issues (Streissguth, 1997). These areas will be discussed in greater detail.

Housing

Adults with FASD are known to have great difficulties in obtaining and keeping stable housing (Streissguth, 1997; Brinda, 2006). Because of the primary and secondary disabilities of FASD, adults with FASD have difficulty maintaining stable housing. For example, interruptions in school attendance, mental health problems, problems maintaining employment, problems handling money, drug and alcohol addictions, inappropriate sexual behavior, criminal charges and/or convictions can all negatively impact housing stability. Many young adults with FASD live with their parents and this causes increased stress on the family unit. For example, a Saskatchewan couple in caring for their dependent twenty-seven year old daughter with FASD has forfeited career ambitions and experienced a loss of income and breakdown in family relations (Polachic, 2008). In one study, only 8% of adults with FASD lived independently (Streissguth, 1997).

The need for safe, affordable and appropriate housing is critical for many adults with FASD (Clark, 2003). Support should be provided on an individual basis because FASD is a continuum, and not everyone will require the same levels or types of supports. A

study found that providing supports to women with FASD resulted in outcomes including “decreased alcohol and drug use, increased housing and use of contraceptives, and improved medical and mental health care services” (Grant et al, 2004, p.507).

At CUMFI Wellness Centre, adults with FASD are given support in obtaining and maintaining appropriate housing. This research will try to determine what is needed in providing supports to adults in the area of housing. A proactive approach would be more financially sound than a reactive approach where society has to pay the cost for housing these individuals with social services or in mental health or custody facilities.

Employment.

The transition from school to work is often too difficult for the individual with FASD (Streissguth, 1997; Malbin, 1999/2008; Brinda, 2006). Developmentally, the individual with FASD is likely behind in many areas due to their cognitive abilities (Malbin, 1999/2008). In addition, their IQ may be too high for them to qualify for assistance but yet they can have serious limitations in their adaptive skills that require them to have employment support (Brinda, 2006).

The need for employment coaching and assistance for this population is great. Individuals with FASD may display inappropriate social skills on the job that can get them fired (Streissguth, 1997). Memory gaps, resistance to change and inability to follow directions are other possible problems. In addition, sensory issues such as a loud work environment or too much visual stimulation can cause individuals with FASD stress and dysfunction in the workplace and need to be understood by their employer.

To help ensure success of an adult with FASD in the workplace, a job coach is often crucial. Skills are best taught by modeling. “Careful instructions, tireless

demonstrations, and tangible rewards are the glue that unifies the work experience for individuals with FAS/FAE and leads to the internalization of the activity” (Streissguth, 1997, p. 194). At the CUMFI Wellness Centre, support is being given to individuals in finding and maintaining employment.

Health

Adults with FASD may not take care of their health. They may have health problems related to their disability such as a problematic nutrition, speech and language needs, dental issues, substandard immunity, high pain tolerance, chronic infections, etc. (Lutke & Antrobus, 2004). In my work as an educator, I taught a young lady with FASD who had a cleft palate. She suffered from speech difficulties and dental problems. I advocated for her by helping her set up dental appointments on her own and helping her figure out how to get there using the city transit system.

Individuals with FASD often have poor sensory skills and a low or high pain tolerance (Malbin, 1999/2008). They may need reminders on how to dress for the weather. They can be easily overwhelmed by stimulation (Streissguth, 1997). For example, noise or lots of visual stimulation may cause them to shut down or escape. My students volunteered at the Good Food Box and were in a busy environment with other volunteers packing boxes of produce. One of my students with FASD kept running away until I realized that he was over-stimulated and gave him an opportunity to go into a quiet place when I saw him starting to get upset.

Inappropriate and risky sexual behavior can be another health issue for adults with FASD. Their cognitive disability can lead them to misinterpret cues and not understand other people’s boundaries. They are at risk for experiencing sexual abuse or sexually

abusing others (Streissguth, 1997). Supports to safeguard them as much as possible against STD's and to instruct them on birth control are needed (Lutke & Antrobus, 2004; Grant, et al., 2004). They are vulnerable to being manipulated by others (Fast & Conry, 2009).

Eating properly and engaging in healthy leisure activities are areas with which individuals with FASD may struggle. Supportive programs can also assist adults with FASD in these areas. For example, the CUMFI Wellness Centre in Saskatoon provides mentors to adults with FASD to help with daily living skills including nutrition, grocery shopping, cooking, and food safety. Providing opportunities for extracurricular activities such as dance, music, sports or computers can help to develop pleasurable skills for a lifetime of healthful recreation and the satisfaction and self-worth of goal-directed behavior (Streissguth, 1997).

Mental Health

The link between FASD and mental illnesses has been well-documented (Famy, Streissguth, & Unis, 1998; Streissguth, Barr, Kogan & Bookstein, 1997; Barr, Bookstein, O'Malley, Connor, Huggins, & Streissguth, 2006; O'Connor & Paley, 2009). In one study, it was found that 90% of patients with FASD had mental health problems (Streissguth, Barr, Kogan & Bookstein, 1997).

Adults with FASD face a high degree of stress from internal and external factors that often compound into mental health issues. Increased vulnerability to depression, anxiety, mood disorder, antisocial behavior, suicide attempts and substance abuse problems have been noted in individuals with prenatal alcohol exposure (O'Connor & Paley, 2009). In the Grant et al. study (2005), young women with FASD showed higher levels of

psychiatric distress relative to other at-risk populations. A study on suicidal behavior found that individuals with FASD had a ten times higher lifetime rate of suicide attempts than the general population (Merrick & Kandel, 2007, p. 237). This research finding portrays the need for supports for this group of people.

Individuals with FASD have a lifelong cognitive disability that puts them at risk for mental health issues. Society must help them by providing diagnosis and offering appropriate services. A mentorship program can help with mental health issues by providing an adult with FASD someone to talk to about issues to help them make positive choices and to connect them to mental health services if needed.

Substance abuse

Substance abuse is another secondary disability of FASD (Streissguth, et al., 1997). Thirty-five percent of adults and adolescents with FASD were found to have alcohol and or drug problems (Streissguth, Bookstein, Barr & Sampson, 2004). In another study, the prevalence of adults with FASD was reported to be 36% (Clark, 2003). Problems arose if the individual with FASD experimented with drugs (Clark). Individuals with FASD are often victims of negative peer pressure and have a need to fit in and be accepted by others. This can lead them to abuse substances.

Prenatal alcohol exposure can lead to adolescents and adults with FASD developing drinking problems (O'Connor & Paley, 2009). O'Conner & Paley found that adolescents whose mothers drank three or more drinks on occasion while pregnant were at increased risk of binge drinking as adolescents than those whose mothers consumed less alcohol. In addition, there was a strong correlation between maternal binge drinking and alcohol use disorders in their adult offspring (O'Connor & Paley).

Support programs can help the individual with FASD to manage their social life in healthier and more appropriate ways. Miles, a young man with FASD, schedules activities like sports to keep himself occupied so that he can manage his addiction issues (Himmerreich, 2008). “Young people who receive responsive prevention programs can avoid or at least lower the chances of experiencing the devastation that alcohol and other substance use can visit upon themselves, their children, their families, and larger society” (Schinke, Schwinn, & Cole, 2006, p. 159).

Legal issues

It is unacceptable that 60% of the individuals with FASD in a study had experienced trouble with the law (Streissguth et al., 1997). It is unfair that their impaired decision making, inability to learn from consequences and impulsivity makes them at-risk for breaking the law. Adolescents and adults with FASD often become involved in crime and spend time in custody. This can be related to their trusting nature when they get recruited by more sophisticated criminals to do their dirty work (Conroy & Fast, 2000). I recall a foster student with an FASD diagnosis whose guardian was frustrated with him when he continued going across the street to a lady's house to deliver drugs for her because, in his opinion, this lady was his friend and bought him McDonald's. He seemed to have no awareness that he was being taken advantage of. I watched him lose his foster placement because of this and experience more turmoil in his already difficult life.

Conroy and Fast (2000) state “perhaps the greatest injustice during sentencing to a person with FAS/FAE is to be treated like everyone else.” Correctional officers, lawyers, judges and others who work in the justice system are beginning to understand the implications of FASD and this is making a difference. In many cases, to help adults and

adolescents with FASD we must adjust our ways of dealing with them rather than expecting them to conform to society and setting them up for failure. Resiliency for the FASD population is in large part helped by caring members of society to understand this disability and pro-actively provide structure before the problem arises. This research will look at how the advocacy and support of a mentor can help adults who struggle with justice issues.

Money Management

Individuals with FASD often struggle with managing their finances (Wright et al., 2004; Bartlett & LeRose, 2002). Their impulsivity leads them to buy things that they do not need or can't afford. For example, they may be on their way to pay bills and end up buying rollerblades. A mentor could help the adult manage their finances.

A system can be devised to track purchases and future requests in a notebook with pockets for each month (Schmucker, 1997). Avoiding bank ATM cards and providing the money they need for each day at the beginning of the day is another strategy (Wright et al., 2004). Another idea is to take photos of items that the person has purchased (Schmucker, 1997) as individuals with FASD can be negative about what they have accomplished and may have an unrealistic view of their spending as they have working memory deficits (Rasmussen, 2005).

Proactive Vs Reactive

It seems reasonable that providing supports for adults with FASD is not only cost-effective but humane rather than paying the costs of dealing with secondary disabilities such as incarceration, mental health and unemployment. The lifetime societal cost of fetal alcohol exposure in Canada has been estimated at \$1.3 million per incident case

(Hopkins et al., 2008). Hospital stays costs approximately \$400/day and corrections costs approximately \$80, 000 per adult or youth in custody at \$60, 000 annually. What should be most compelling, however, is the human cost and loss of potential that results when the needs of those with FASD are not addressed.

It is unfair that individuals who are born with brain damage due to maternal drinking do not receive the supports they need. These individuals face enough barriers to experiencing a quality life. It is essential that we determine how to best help adults with FASD. By speaking to these adults themselves, this research will be able to discover what their needs are and how support services can be most effective.

Support Programs in Canada

In the past few years, increased efforts are being made across Canada to help individuals with FASD and their families. Programming is being piloted to help individuals with FASD have better life outcomes. These programs are very much in the experimental stage. A brief summary of some of these programs is detailed below.

In Saskatoon, a supported housing project for persons with FASD was proposed in 2006. This was funded by the National Homeless Initiative of Canada. Groups like the FASD Support Network of Saskatchewan have been involved in this project and continue to advocate for the needs of adults with FASD.

In British Columbia, the Bridge Program has been developed to help young people living with FASD make a more positive transition to adulthood (Hartley & Dewar, 2009). The program offers young people living with FASD and their families, service and support.

In Winnipeg, Manitoba, a program to serve the needs of youth with FASD in conflict with the law is experiencing much success because it is reducing the crime rate for this population (Longstaffe, Harvie, Brown, & Neaut, 2009). These are just some examples of programs that are providing services to adults with FASD across Canada, but there is still much work to be done.

Parent advocates such as Jan Lutke, president of the Canada Northwest FASD Research Network, are active in promoting awareness and developing supports for individuals with FASD. Lutke has also written extensively about her experiences as an adopted mother of children with FASD. Her personal knowledge along with others like her can be found in *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (Klienfeld, Ed., 2000). This book is valuable but it demonstrates that practice is ahead of research in the area of adult supports for FASD. It is critical to conduct research on the best practices and the efficacy of adult support services to guide future developments.

A Mentorship Program in Saskatoon

In Saskatoon, the CUMFI (Central Urban Métis Federation Inc.) Wellness Centre provides services for older youth and adults with cognitive disabilities. Although CUMFI is a Métis organization, adults at the Wellness Centre do not need to disclose their ethnicity to maintain services. Fetal Alcohol Spectrum Disorder is a universal disorder that can impact anyone. The CUMFI Wellness Centre is coordinated by Eunice Bergstrom and has been operating since April of 2007. The program is based on a mentorship approach which means that adults with a cognitive disability are partnered with a mentor who supports them to have a better quality of life.

Staff members at the CUMFI Wellness Centre build relationships with individuals who have cognitive disabilities, many of whom have FASD. The staff members help these individuals obtain and maintain housing. They also help them with employment, recreation and decision making. Mentors help the adults with cognitive disabilities access services and resources such as income security. They work with them to help them pay bills, attend appointments and develop to healthy relationships and living patterns.

There is a great deal of work to be done in evaluating what support is effective for adults with FASD. There are many people who are laying the groundwork but much more advocacy is needed for these individuals to have the best future they can have. This ethnographical study of the mentorship program at the CUMFI Wellness Centre will add to the literature on how mentorship impacts adults with FASD and how to improve the supports to this population.

Chapter III: Methods

This chapter will outline the methods used for this study. It will lay out the research paradigm as being advocacy focused. This study will use an ethnographic approach, and specifically a critical ethnography and the purpose for using this approach will be explained. Reflexivity was employed to make my position transparent to my participants and to readers. Finally the methodological procedures will be detailed.

Advocacy/Participatory Paradigm

This research focused on advocating for both awareness and action to improve supportive programming for adults with Fetal Alcohol Spectrum Disorder. My research paradigm is advocacy and participatory since the goal of my research is to give voice to a marginalized group of people, namely, adults with FASD. I will employ a collaborative process whereby my participants will have an active role in the research. My participants will be involved throughout the study.

Ethnographic Research Approach

My research will employ an ethnographic approach. In particular, I will employ a critical ethnography which will be explained in more detail. By entering into firsthand interactions with people in their everyday lives, ethnographers attain a deeper and more meaningful understanding of their participant's lives than by using any other method (Tedlock, 2000). Ethnography "combines research design, fieldwork, and various methods of inquiry to produce historically, politically, and personally situated accounts, descriptions, interpretations, and representations of human lives" (Tedlock, p. 455). Ethnographers begin the research process with a problem in mind but keep an open mind

about the group they are studying and try to understand and learn about the daily lives of people from an insider's perspective (Fetterman, 1998).

Adults with FASD who have mentorship services at the CUMFI Wellness Centre can be viewed as a particular cultural group as they share a 'home base' of services at the centre where they are free to drop in on a daily basis which many of them do. Having a specific cultural group to study is important in ethnographical research. Adults with FASD also share common characteristics of their neurological damage and they all face similar life challenges as a result of their disorder.

Critical Ethnography

My research employs a critical ethnographic approach, where I advocate for a group of people and call for social change to help individuals with FASD. Thomas (1993) describes critical ethnography as a type of research in which the authors advocate for the rights of a marginalized group in society. "Conventional ethnography *describes what is*, critical ethnography *asks what could be*...Conventional ethnographers study culture for the purposes of describing it; critical ethnographers do so to change it" (Thomas, 1993, p. 4) Adults with a cognitive disability such as FASD are marginalized and often have to struggle for things that the dominant society takes for granted. The intention of my research is to put forward the needs of adults with FASD by understanding their lives from lived prospective and to provide deeper insights into needed supports.

I chose a critical ethnographic approach as it best fit my research goals to provide awareness for adults with FASD and to advocate for their needs. I gained access through the gatekeeper, Eunice Bergstrom, the program coordinator of the CUMFI Wellness Centre in Saskatoon. This program delivers mentorship to adults with cognitive

disabilities including adults with Fetal Alcohol Spectrum Disorder. Through meetings with Eunice, I established a relationship and a mutual trust to begin my research.

I planned to spend a minimum eight months at the CUMFI Wellness Centre to become ‘acculturated’ into the climate. Ethnographers need a significant amount of time to devote to fieldwork and to engage in the lives of the people they are studying (citation).

I ended up spending eighteen months interviewing mentors and adults with FASD at the CUMFI Wellness Centre. It took a great deal of time to have the opportunity to interview the adults with FASD. Although the adults with FASD were willing to help, their lives were often filled with other pressing needs that took precedence over the study. For example, they could be moving, looking for work, handling relationship issues, substance abuse problems or spending time in custody. I discovered that it is time consuming to study adults with FASD since their personal lives can be chaotic, full of moves and personal upheaval. In addition, they may forget appointments at times due to their memory problems. These are the reasons that my study took longer than I had initially predicted. I conducted approximately two interviews per month during this time period.

Reflexivity

As is common to ethnographic studies, I began my research by employing reflexivity. Reflexivity can be viewed as a tool where researchers make “transparent the values and beliefs” they hold “that almost certainly influence the research process and its outcomes” (Etherington, 2007). I let my participants know my personal reasons for conducting this research and what I hoped to accomplish with it. As I spent quite a bit of time with my

participants and became a part of their local and social world, I was mindful of the effect I was having on them. I made it clear to my participants how long I would be with them and what my role and purpose would be.

Methodological Procedures

Participant selection.

I recruited my participants through the CUMFI Wellness Centre as I needed adults with FASD who were receiving mentorship for my study. Adults with a diagnosis that fit under the FASD umbrella term were recruited. In this study, six adults with FASD were interviewed.

- Three male and three female
- The youngest was seventeen years old, one twenty-five years old, one twenty-seven years old and the others were likely in their twenties or thirties
- All had been in long term foster care or adopted
- Two were in a common-law relationship at the time of the study
- Five have a child(ren); four have little or limited contact; one is single parenting
- One has a grade ten education; one has a grade twelve modified education; one a partial grade twelve; one was taking high school upgrading; the others unknown
- One had been employed for part of the study.
- One was incarcerated and then in a mental health institution; three disclosed justice issues

- One had schizophrenia; one had anxiety symptoms
- Four had experienced substance abuse issues
- One disclosed being a gang member in the past

During the consent process, I explained what the research steps would involve. Staff members were available, during this time, to help ensure that my participants with FASD understood what they were agreeing to. I developed a special consent form for the adults with FASD using simple language and then checking in a point form fashion for their comprehension (see Appendix C for consent form for adults). I read the consent form to all the adults with FASD to ensure understanding.

Staff members, who work at the CUMFI Wellness Centre, also participated in the study. The staff at the CUMFI Wellness Centre included four mentors, one community liaison worker and a program coordinator. The staff members were also guided through a process of understanding their involvement and their rights. They too signed to give their consent (see Appendix D for staff consent form). I invited all staff to participate in this study, six staff members were interviewed.

Data collection

I interviewed individuals with FASD and staff members at the CUMFI Wellness Centre. Two to three, forty-five minute interviews were conducted with six adults with FASD and six staff members who provided support for these adults. Most of the interviews for the individuals with FASD took place at the CUMFI Wellness Centre. Individuals with FASD like routine and often feel more at ease in a familiar environment (Malbin, 1999/2008). Two of these interviews took place at the Saskatoon Correctional

Centre. Three of the interviews took place at the adult's residence for their convenience. Interview questions for adults with FASD are attached (see Appendix E).

I worked to make the participants feel safe to share information that might be unfavorable to the staff at the CUMFI Wellness Centre. I visited the Wellness Centre and chatted with them in order to establish rapport and let them know me and my purpose. I assured the adults with FASD that the information they would disclose to me would remain confidential and that it would not affect their services at the Wellness Centre.

Two, forty-five minute interviews were also conducted with six staff members at the CUMFI Wellness Centre who were willing to participate. This included the program coordinator, a justice worker and four mentors. All of the interviews were semi-structured. The staff interview questions are attached (see Appendix F). All of these interviews took place at the CUMFI Wellness Centre.

The interviews were recorded with an Olympus WS-210S Digital Voice Stereo Recorder and then transcribed by myself. During transcription, effort was made to remove information that might affect the anonymity of the participant. In addition, participants were able to read over, or have someone read over their transcripts, to provide them the opportunity to add, change or delete any of their statements. This was to help to protect their anonymity and best interests. When the participants were satisfied with their statements, they signed a transcript release form (see Appendix G for transcript release form for adults and staff).

Finally, I invited the adults with FASD to share any items such as a poem or a drawing to express themselves. With their permission, some of these items were published in the final report.

Data Analysis

The interviews were transcribed. Participants had the opportunity to add, change or delete anything they said as an additional safeguard. After this, the transcriptions were read and margin notes and initial codes made.

Topic coding was used to code data for easy retrieval (Richards & Morse, 2007). A concept map was designed to help organize major topics such as: appropriate housing, employment, leisure activities, relationships, self-esteem, daily living skills, money management and accessing services (see Appendix H). In addition, I added some themes that arose during the data collection such as addictions, mental health and justice issues. The transcripts and observations were interpreted to find patterns of the culture of adults with FASD and their mentors.

To ensure confidentiality, the data was stored on my computer with a password and in a locked filing cabinet. Participant's names were not attached to any of the data. The data will be stored at the University of Saskatchewan with Dr. Ivan Kelly in a secure place for a minimum of five years if there are questions about my study.

Writing and Reporting

During the writing of the thesis, I used many verbatim excerpts from the interviews to emphasize common themes and issues that have arisen. Pseudonyms were not used as I was working with a small population and this might increase the chance of a loss of anonymity. Instead, I described the participants as either adults or staff members. Observational field notes were also included in a small degree to add to critical findings.

My final report passed defense on February 28, 2011 at the Department of Educational Psychology and Special Education at the University of Saskatchewan. I plan

to publish my thesis so that it can help others who are working in the area of building supports for adults with FASD. I also plan to write and publish a journal article that will add to the literature on adults with FASD. In addition, I hope to use the information I have gained in my study to present at conferences or workshops.

As a critical ethnographer, my intent is to use my research to build awareness for this population. I will use my research to advocate for social change for increased supports and programming to improve the quality of life of adults with FASD and their families. I plan to approach government with my study to advocate for awareness and support for adults with FASD.

Validity, Rigour and Credibility

The validity and credibility of quantitative research requires specific procedures and also the sensitivity of the researcher. To do ethnographic research, the researcher must spend an adequate time in the field and must engage in a continual ethical process of reflexivity, continually checking with participants on the accuracy of material being gathered and the researcher's interpretations. To ensure the validity and credibility of my ethnographic study, I have followed these validity strategies: (a) prolonged engagement (b) triangulation, (c) member checking, (d) clarifying and articulating researcher bias, and (e) the use of rich, thick descriptions (Creswell, 2007).

My ethnographic research employed prolonged engagement with individuals at the CUMFI Wellness Centre in Saskatoon. The interview process took eighteen months in which time I was at the CUMFI Wellness Centre approximately twice a month. By conducting two or three interviews with each participant, I had the opportunity to attain a more realistic view of their thoughts on the mentorship process. Participants in my study

adjusted to my presence and seemed to feel comfortable in sharing their true feelings with me.

Another method of validity that I employed in my research was triangulation. “If themes are established based on converging several sources of data or perspectives from participants, then this process can be claimed as adding to the validity of the study” (Creswell, 2007, p. 191). By using participant observation as well as interviews and using materials such as poems or artwork from the participants, I collected different sources of data. This improved my ability to answer my research question about the effectiveness of the supports given for adults at the CUMFI Wellness Centre.

In addition, I also used triangulation by comparing and checking perspectives from both the adults and the staff. This was especially useful as individuals with cognitive disabilities may fabricate their narratives as a result of their memory problems. It was also useful for me to ensure that I did not overlook inconsistencies in what adults said about the mentorship as compared to what staff said. Staff may have a vested interest in promoting the work they are doing at CUMFI Wellness Centre. By hearing from both adults and staff members, I had a richer understanding of the mentorship program.

Member checking is another process of validation that I used in my study. My participants were able to verify that the ethnographic study that I have produced was reflective of their experiences. This is an important part of ethnography and the process of reciprocity. Reciprocity can be described as a process of building trust and cultivating relationships and genuine interest in one’s participants (Schwandt, 2001). By giving my participants opportunity to engage in member checking, I showed reciprocity.

As an ethnographer, reflexivity is important and I was open and honest with my participants about why I was doing the research. I told them my personal and professional interest in wanting to help adults with FASD have a better quality of life. I feel that this honesty added strength in my research. My participants knew what my goals were and were able to decide if they wished to share in the attainment of those goals. I told the participants that my purpose was to find out if the supports they were being offered at the CUMFI Wellness Centre were useful and how these supports could be improved. As I wrote my study, I exposed my hopes – my wish to use the findings to improve and build on supports for adults with FASD.

Finally, my writings include rich, thick descriptions. My findings were illuminated and illustrated by excerpts from my participants. These participant excerpts improve my validity as they demonstrated that my findings were firmly anchored to the data. My report will enable someone who has never been to the CUMFI Wellness Centre, to have a better understanding of the particular social world of adults with FASD engaged with their mentors. By using dialogue from the adult participants with FASD, I gave them a voice that can help to build understanding and awareness to others of what it is like to live with prenatal alcohol effects. The voice of adults with FASD comes through in my work as powerful and authentic so that those of us who are working for them can better understand their needs.

Chapter IV: Results

Background

Interviews were conducted with six staff members and six adults from the CUMFI Wellness Centre between July 2009 and December 2010 in Saskatoon, Saskatchewan (See Appendix B for an overview of the CUMFI Wellness Program).

Definitions

Adult: For the purpose of this study, an adult refers to an adult with a diagnosis that fits under the Fetal Alcohol Spectrum Disorder who is receiving mentorship at the CUMFI Wellness Center. It is important to note that all of the adults in this study have been affected by fetal alcohol exposure although the CUMFI Wellness Centre provides services to adults with cognitive disabilities in general.

Adults are unique individuals. Although each adult in this study has a diagnosis in the fetal alcohol spectrum, each of them is affected to a varying degree and each has different needs and abilities. The adults with FASD in this study should not be seen as representative of the entire population of adults with FASD. They may be receiving more support than other adults with FASD so this could mean that they have higher needs or it could also mean that they are doing better than individuals without supports.

Mentor: For the purpose of this study a mentor refers to a staff member at the CUMFI Wellness Centre. This term has been used for the mentors, the program director and the justice worker to protect their anonymity although each role is specific. I have also used the term staff member interchangeably with mentors.

Housing

Adults Perspectives

Adults at the CUMFI Wellness Centre have a variety of living situations.

I'm in a roommate situation right now. My roommate owns the house. I'm basically renting. I have my own room, groceries, tv in my room. It is more like a boarding situation where I look after my own accommodations.

This adult feels good about where he is living now. He has been there for three months. He believes that none of his roommates will steal from him. He has groceries and a place to sleep at night. Many adults mentioned the security of living in a safe place. This adult is also interested in moving into the Hessdorfer House, a four-suite apartment building. The Hessdorfer House is a housing unit that was started and maintained by the CUMFI Wellness Centre. It offers subsidized living and has a "house parent" who lives on site and is available for the adults.

I'm on the list to move into a housing situation where I am able to have my furniture ready for me and have my mentor come knock on my door, pick me up. A curfew, no alcohol, no drugs, more of a secure setting that CUMFI invested into. I think because of my disability it would help me excel in life.

Another adult is feeling safe in her housing situation which her mentor helped her secure:

It's affordable housing. I needed a place ASAP so they helped me right away and it was like "Oh, thank God." And it was actually supposed to be for me and her but stuff happened. Well my mentor said something about CUMFI and that they do that for housing and she said that she would give me an application form and help me to sign it and everything. So she helped me with that. And then she kept bugging them because I really needed a place at the time and I got a place.

This adult had been living there for four months when I interviewed her and she was pleased with her apartment and living situation:

Ya and I was so happy. It's tiny and it's perfect. Yes there are curfews and rules that you have to follow otherwise you will get kicked out and I like that. I love rules. I have rules here too.

Her only difficulty is with some roommates who are staying with her:

They are complicated because they are two adult men living in my house which is basically for my baby and they should be paying some bills by now. It's been past a month for each of them and they haven't given me one cent yet. Neither of them have jobs so that's pretty sad. If I could work, I would but I have a baby so... Well, my friend, he didn't even ask to move in, he just moved in so that was really rude of him and he's not talking about paying any bills yet and I'm like, "Okay..." so I'm going to like talk to him about that today because I am really sick of him. He's not following the rules and that's kind of... not good.

This adult's biggest housing issue was having people stay with her that she did not want.

The mentors mentioned that the adults with FASD they work with often let people stay with them and get into problems this way.

The adult talks about her last living situation:

The last place that we lived in was a piece of crap. All the stuff, the bathroom. There was something wrong with the toilet. There was something wrong with the sink. There was always this gross smell and there was always like flies in the house and we didn't know why. The washer and dryer we shared with other people who lived next to us. There was one house and two people lived in it. It was complicated because the next door neighbors, they would complain about everything. If we put the music too loud or something, they would complain about it. And then it's weird because then they'd have parties and they'd be drinking and it's not right because it was a family place and you're not supposed to be drinking so that's why we moved.

Another adult is having struggles with her living situation because she does not feel safe.

There's people coming to the window now looking for (her boyfriend). Just his buddies and I don't like that. So I know I have to move next year or get a place. They're coming late at night and they're waking me up banging on windows so it's not safe for me there actually 'cause I'm there alone.

Her boyfriend, although she mentioned that she is not sure if she can call him that anymore, is in the hospital. He had his legs amputated for diabetes. She is having difficulty covering the bills herself.

We got separate cheques but the thing is how is he going to pay rent when he is in the hospital? I'll have to talk to the landlady and ask about that. See if she can put it off a bit till at least he gets out.

This adult has recently moved to Regina but has been taking the bus back to Saskatoon to connect with her supports at the CUMFI Wellness Centre. While in Saskatoon she is staying with her cousin and is not in a good situation there:

It's not looking good right now. They're doing stuff I don't even like doing [intravenous drugs] so I might have to get ahold of my other cousin up in Meadowgreen but she's not even answering my calls either so I've got to stop calling her apparently. They said they quit. But I found out this morning that they were rushing around with needles in their hands and I took off. I said I am not going to be around for this.

When asked if her cousin was also using the intravenous drugs:

No, it is just people off the street that usually go up there. Found out that all my smokes got stolen last night. I trusted them, "nothings going to happen here." My smokes got stolen. I don't need that right now. I needed those smokes.

Right now she is staying with a cousin in Regina:

Because she helps me out. I'm off and on but last night we had a big fight. She wanted to hit me because.. I just hate this...There is nothing to go home to. [My boyfriend] is not home and I am always at the hospital and that's depressing. My cousin asked me to drive her around all night and that's kind of tiring too. And

her kids are starting to throw stuff at me and I get mad at them and then she tried bringing my son into it.

When asked if CUMFI Wellness Centre has been involved in her housing in the past:

Ya they did. They found me the Infinity House so and then I found myself twice at the Lighthouse when I got kicked out of the Infinity. Actually I quit that Infinity. And then The Y [YWCA] I got sent to. I am trying to get into the Y. [I spent] one month there at the Y then I moved to Regina.

Infinity House is a non-profit organization in Saskatoon that provides secure housing and programming to single Aboriginal women and their children. Lighthouse Supported Living Incorporated provides emergency, transitional and long-term housing. It provides services for individuals with FASD, brain injury, mental health and others in Saskatoon.

In Saskatoon, the YWCA offers emergency shelter to women, children and youth at risk.

This adult has moved many times and recounts her housing history:

Ya we moved house to house lately. The other place was at the [address] before I got sent to the Infinity House. Well I moved into the Infinity House after a waiting list. One day after my visit, my mentor came to me and said, "How soon can you pack your bags?" And I said, "What are you talking about?" "Do you want to move?" I said, "I don't know, I'm sick of moving." "Well you got into the Infinity House." (the mentor said) I said, "Ok, I'll pack my bags." The next day I moved in so it's pretty cool. But then (her boyfriend) couldn't afford the rent there so he had to move to the Salvation Army and then he moved to (address) and stuff happened over there.

The adult moved out of the Infinity house due to a conflict with another tenant:

Being called names, every name in the book and stuff on the street and everything so I said, "I want to move." So I moved out because there was just too much stress over there and stuff. One person over there, she caused a lot of stress for me and everything. I had to prove to them that I am not the one making all this stuff up. I moved out. I said, "I can do better than this."

This adult has had a lot of instability in her life. It is difficult to find housing for adults with FASD due to the nature of their disability. Cognitive deficits such as a lack of comprehension of abstract concepts such as time and money can lead to difficulty maintaining housing. Individuals with FASD are often overly trusting and can be frequently taken advantage of by others who will use them for money or move into their place of residence causing them problems with their landlord (Streissguth, 1997). Difficulty with cause and effect and impulsive behavior can also lead to eviction (Brinda, 2006). The adult with FASD may forget to pay the rent, be disruptive or act inappropriately without thinking. Mentors talked about the difficulties of finding adults a place to live when the adults burned their bridges at some of the places around the city. It gets more difficult to find housing over time if an adult has been evicted.

When I conducted another interview with the before mentioned adult with FASD, I discovered she hadn't eaten for days. She was falling asleep during the interview. She was obviously distressed – tired, nervous and anxious in her living situation. Her mentor went to make her some food. She was in crisis because her energy and power had been shut off at her residence in Regina. She had been very cold in there, it was winter at the time and she said that her food was spoiling in the fridge. During the interview, her mentor made some calls to Regina to get her power and energy reconnected for survival reasons.

Here is another example of an adult who has been in many different living situations in a short time period. He had been living in housing provided by the Salvation Army, in the hospital before the first interview. He had been living in a private care home for three

of four mouths when I first interviewed him. His trustee (from the Salvation Army) had found the place for him:

I don't mind it but I'd really like to get my own place. They cook your meals and do your laundry and you sit with the rest of the adults and eat supper with them.

One of the conflicts of housing experienced by adults with FASD is the desire to be independent balanced with their need for support. His reasons for wanting to find his own place were: "Well I can cook my own meals and do my own laundry and not have to live with a bunch of other people. I figure I'd like that." He said that he would have difficulty in finding a place because he has "not many references." He was in corrections during the second and third interviews. After he was released from corrections, he was sent to a mental health centre and now is in a mental health care home.

Another adult was living at the Hessdorfer House with her common-law partner at the time she was interviewed. They have since moved out for more independence. This adult talks about her experience living at the Hessdorfer House:

I guess it is between a house and a suite. Actually for me I feel kind of good. The only thing I kind of wish they would change about it is that the ones who live there always come down to our place and start complaining when they have problems upstairs and then they come down and start complaining to us and stuff like that. They (mentors) always tell us there are rules. There is supposed to be rules that nobody goes in anybody else's apartment or goes and tells other people their troubles and that but a lot of them don't seem to listen.

Despite the complaints the adult feels alright about living at the Hessdorfer House:

Actually I find it better than some of the smaller places right now because right now for housing, a lot of other places – hectic to try and even find a place. We can get that housing supplement that helped with the rent. Actually I didn't know about it until CUMFI told me about it.

Before the CUMFI Wellness Centre was involved, the adult's housing situations was:

Not very good actually. I was living with my brother and them and that is one person I will never move in with again because it was the worst time to live with him. Well when I was living with him he literally tried to strangle me to death in front of my daughter.

She compares this to the security she feels at the Hessdorfer House which is monitored:

I find it's [the Hessdorfer House] actually safer because they make sure certain people, if they don't want certain people around there. They make sure of that. Ya and [house parent] is actually the one there. Actually with him there, he's helped a lot, me and my boyfriend a lot actually. Actually right now he is helping us with couples counseling actually. So it's actually pretty helpful I think.

The 'house parent' is also a mentor at the CUMFI Wellness Centre and he does couples counseling for the adult and her common-law. He counsels them at their residence, the Hessdorfer House or at the CUMFI Wellness Centre.

Another adult has recently moved into the Hessdorfer House and he says, "It's all good over there." He appreciates his new living arrangements:

We got the place, it was already furnished. Had couches, a flat screen t.v., bed, table, everything. Coffee maker, what else? All kinds of stuff, utilities.

The safety and security of living at the Hessdorfer House seems to be an important feature to the adults:

Comfortable, safe. Feel better being away from my sister. Things were too small over there. Tight space.

His mentor helped him find the place:

He has been trying to find a place for me and [my girlfriend] for awhile until we found this place.

Staff Perspectives

Housing was identified as a critical issue facing adults with FASD. Housing gives adults with FASD structure and security and enables them to progress in their lives. A staff member stressed the importance of stability with housing: “If you don’t have it how can you move on?”

Housing can be a very prominent issue in their lives. People with FASD want to feel safe and if they are not feeling safe, they want to move. Sometimes what happens is people don’t end up with the best references so they get caught in a situation where they don’t have references, they don’t have housing. How do they even start with housing?

Another staff member said that with proper housing “a lot of progress can be made.”

Barriers to housing include the financial limitations of the adults, the housing shortage, the unstable nature of adult’s lives, landlord’s unwillingness to rent to them and facing eviction for various reasons. Finding a landlord who will take certain adults is rare. Securing housing for adults with FASD can become even more difficult over time.

Some of the people have burnt their bridges with the housing so it’s a real challenge to find housing for somebody with FASD.

Some adults with FASD may need to live in group or transitional housing such as The Salvation Army, The Lighthouse or Tamara’s House. To make things more difficult, mentors say that their adults often refuse to go to a group home or a housing place.

They say, “No, I’m not living there because they’re too bossy.” You have to try to talk to them in a way where it will help them.

In regards to housing, mentors have “helped them get in contact with services that they might not know is out there.” When adults need to move, “We also help them with the move form from social services.”

A lot of hoops you have to jump through when you get into housing. So we help them with that. We help them go down to social services. We might go with them just in case they don't understand something the worker is saying. They might be embarrassed to speak up and say they don't understand that but then afterwards when we are in the car they'll be like, "What did that mean?" and we'll help them clarify.

financial need.

One of the main challenges of finding appropriate housing is adult's inadequate finances.

Most of the adults that we work with are on social assistance and they only get x amount of money therefore they need an income supplement or a rental supplement.

In addition to not having enough money for adequate housing, adults also struggle with managing their money. Mentors may take them to pay bills, set them up with a trustee and help them with budgeting.

Some don't pay their bills. They're too embarrassed to say, "How much money do you need to pay your cable bill?" They don't know how to budget. This is where the mentors come in."

Mentors also help their adults to make reasonable financial decisions about housing. For example, an adult was offered to tent in his sister's backyard for twenty-five dollars a night. The adult's mentor told him that this was too much. Without intervention, the adult would have likely agreed to this arrangement and been taken advantage of.

clients' anxiety of finding housing.

One of the mentors talked about the anxiety that their adults face when they are given an eviction notice. The mentors see their adults fixated on worrying about where they are going to go.

We have to talk to them and calm them down. And say, “We are going to take this step by step.” We’ll give them steps and help them calm down...

When I visited an adult who was incarcerated, he had his knuckles bandaged up. Staff at the correctional centre told me he had been punching the wall that morning. He had hoped that his trustee could help him find a place to live. He was upset about where he would live if he was released after his court date the following day. I could see the extreme anxiety that he was facing.

social services.

Mentors recommend changes to the social system that could improve the lives of adults with FASD by removing barriers. For example, adults are not motivated to work when they can collect more money and live in a better place by staying on social services.

The costs are too high for them to get a job. There is no ambition for them to work after that. I have a guy staying at this group home and it’s one thousand one hundred dollars and that’s tough for me even working. Social services - they pay because it’s a level four home. Where’s the ambition to go get a job for six hundred every two weeks clear? He’s going to get less money working then sitting on social assistance and doing nothing.

Mentors at the CUMFI Wellness Centre have talked to social services about keeping their adult’s file open if they get a job. Then if their adult gets laid off or something happens, they don’t have to “go through so many hoops to get back on social assistance”. This would create more incentive to work and more security.

lack of appropriate housing.

With the rise of housing costs in Saskatoon, affordable and available housing has become a crisis situation for many adults with FASD. Finding safe and appropriate housing is even more problematic:

Some places have mold, some places have insects.... A lot of lower rental properties are basically in the hood therefore the safety features – they can't walk around at night, there is always the alcohol and drug use in the area, drug trafficking..

eviction.

Adults have been evicted for a variety of reasons. One reason was due to a general lack of upkeep. Mentors have tried to help in this area.

We kind of scrubbed the whole house and got rid of things that were piling up and helped organize and got a few things to help keep it that way, maybe little containers and stuff. And actually helped them repair some damage or helped them to repair it themselves but sometimes they just need help in just getting it done, just executing it.

Another common reason for eviction was the issue of adults having too many people at their residence.

They end up having a lot of people in the apartment and being evicted. A lot of times they're easily manipulated into letting other people stay over [and] therefore breaking the rules.

Mentors act as a middle man to help with issues between landlords and their adults.

Mentors intervene to help resolve conflicts before eviction occurs. They can help in the communication process between the two sides.

dealing with landlords.

A staff member mentioned that one of the biggest barriers to housing was to have “people look at them as having a disability.” Mentors often go with their adults to look for housing.

Sometimes I think it helps people to get the place to rent in the first place because if a young guy goes with say, two middle aged women to look at a place, they are much more likely to get to rent it than if they had gone by themselves with ear piercings and lip piercings and that kind of thing. It just lets people know that this person has somebody else in their life who will probably be there. If they can keep up a relationship with these people, well they are probably trustworthy.

Another barrier is the difficulty that many adults have in “talking for themselves.”

Some of them have a really hard time explaining their situation to other people. Some are afraid to ask for assistance or guidance. Sometimes they get nervous or they don’t understand what the other person is saying and it’s hard for them to really comprehend that they need a place to stay.

Staff members found that their adults could be taken advantage of by landlords. For example, adults have been told that they could stay in a place but only for an extra two hundred dollars a month. Mentors help insure that their adults will not get “stiffed.”

instability often associated with FASD.

Staff at the CUMFI Wellness Centre also commented on the frustration of trying to find housing for an impulsive population. Staff may spend a great deal of time setting up a living arrangement for a adult and then have their adult decide not to take it. Having adults stay in the same place, continuity as one mentor called it, was one main challenge.

Obviously it brings up the whole issue of FASD. People are impulsive. If they’re drinking, then the whole place gets ransacked, then there are evictions. Trying to prevent evictions... there really aren’t places available for adults to live yet that have the full-time support they need. So you see it is two-fold, part of it is their

own impulsivity, issues they have and part of it is lack of places, supports for them. That's the big part is there is not proper housing yet for people with FASD.

This mentor went on to say that in some cases appropriate housing would look like twenty-four hour support, "someone to give them medication if they need, make their meals, and live-in mentors are a big part of it." It is important to note that individuals with FASD are on a spectrum and not all of them would need this kind of intervention but it seems clear that services are still lacking for the ones who do.

As a teacher who works with FASD students, I have noticed that they often have a restless nature and difficulty committing to things. For example, one day a student of mine wanted to stay in school and complete his grade twelve, the next day he decided that he should find work and the following day he moved back to his home reserve. These kinds of situations are quite common. It is not rare for me to be teaching a student with FASD and have him/her disappear. I will later find out he was on the street in a gang, incarcerated or in one case, on a bus to search for his biological father in British Columbia who he had never met and did not have an address for. I can imagine the difficulty of setting up housing and stability for individuals with FASD.

supported housing.

All of the staff at the CUMFI Wellness Centre saw the need to have specialized supportive housing for adults with FASD as essential. The CUMFI Wellness Centre is piloting a housing unit that they manage for their adults. This housing unit, called the Hessdorfer House, has a staff person living on-site. This staff person is able to provide supervision and support and is called a house parent. The apartment itself was purchased and renovated through the National Homelessness Initiative. Social Services covers a

portion of the house parent's wages. Adults also rely on disability housing supplements to top off their rent.

We were really forthright with Social Services about needing the shelter rate plus the Disability Rental Supplement because we couldn't afford to keep it going otherwise. It is furnished. Utilities are paid including telephone, television with basic cable and computers with internet. It is exciting because it is a really good model.

One staff member said that "It gives them the independence they need with their disability." Adults have to abide by strict rules or deal with their mentors or house parent. Adults have someone to "go to for help if they are in a tough situation."

It is a safe environment so it is working out well for them, I believe. A lot of times it is just a little thing that they need so they can just phone up the house parent, "How do I do this?" and she is just a phone call away and can run down to the apartment. "Can you help with this?" or "How do you do this?" I think it builds confidence in the tenant as well because they feel secure.

At times, the house parent or the mentors have to deal with relationship conflicts at the Hessdorfer House. This might be in the form of adults gossiping about other adults. As one mentor said, "The adults have a hard time keeping their opinions to themselves." Mentors often mediate between tenants. Conflict arises when adults have too many visitors and are not able to say "no." This is where their mentor and/or the house parent can help them to set and enforce boundaries.

Ground rules at the Hessdorfer House build security for adults. The residence is drug and alcohol free. There is a buzzer that goes off in the house parent's apartment when the outside doors are open and closed. The adults who live there can come and go as they wish but visitors are only allowed to be in till eleven pm. This is helpful to adults who

can be so easily talked into letting people stay with them. This was one of the biggest challenges, not having other people come in at night.

It means that people can't come in at 4 am, other people, not the residents. There are some rules on how long visitors can stay.

Another challenge was ensuring that the adults have food on the weekends. Staff members always make sure that their adults have enough food. In addition, adults can ask their house parent advice, "How should I prepare this food? - the kind of things our Mom's did for us."

Summary of Housing Issues

Both adults and staff saw the benefits of the having supported living like the Hessdorpher House. One of the adults, however, chose to move out of the Hessdorpher House due to staff questioning her partner if he was looking for work. This shows the adult's desire for autonomy and independence versus the staff members desire to help. This need for the adults to have independence versus their need for support is a difficult balancing act. Even though this adult chose to move out of the Hessdorpher House she still spoke favorably of it and is appreciative of the support that was provided to her there.

Adults seemed to appreciate the safety and security of supported living and the assistance in finding appropriate housing. Supported housing has been effective for adults with FASD. All of the staff at the CUMFI Wellness Center saw the need for more supportive housing. Staff at the Wellness Centre saw that the model worked best when the adults were actively engaged in the program. They found that if they had a relationship established with the adults, it was easier to have them follow the rules. In the

same way, staff have discovered that it is not a good idea to let adults live at the Hessdorfer House if they do not have a solid relationship with them.

Education and Employment

Adults Perspectives

Two adults were working at the time of their first interview, one of these on a casual part-time basis. Another adult was taking classes. One was raising her newborn baby. The other two adults were neither employed nor taking training during the study.

One adult talked about her work placement during her first interview: “It’s actually housekeeping. Cleaning motel/hotel rooms.” Three weeks later, she had quit the housekeeping job and found other employment. She found the housekeeping job through Partners in Work Placements. She did not have prior experience in the hotel industry:

Well not motels or hotels and that but I have done cleaning and stuff like what they do. Like at our place right now. I clean the hallways, vacuum and mop the floors. Stuff like that. I do that where we are (Hessdorfer House).

Another adult with FASD talked about his employment history although he was not working at the time of the interview:

What I have found is that I’ve worked for several companies but I haven’t been consistent in what I do. For example, I worked as an account manager for Sasktel for two years and I worked at the bank at the Casino for awhile. I just wasn’t consistent so what CUMFI has helped me do is they have helped me be consistent. They would come and knock and say, “[adult’s name], you need to get up.” Usually I’m a morning person but they’d say, “I’m going to assist you with a ride. I’m going to assist you in getting to your appointment ’cause I understand you.” My brain is all over the place sometimes.

Obviously this adult has lots of abilities and talents. He can be successful but he still faces difficulties.

He benefits from help at the CUMFI Wellness Centre. He identified his need:

It's the structure. My structural environment is what I have difficulty in. If I'm enrolled in a work setting I can excel. I have a very positive attitude as far as a work team. As far as family, I am a father to my three year old daughter. It is the structure I really lack. To put a guideline, a timeline - what I really struggle with my disability.

This adult was successful working at the bank, handling personal accounts but he lost his motivation when the company changed its structure and he began making a lot less money. He was gifted at sales.

I started at Tip Top Tailers. I worked there for about a year. They flew me around [for] training: Canmore, Kananaskis, Calgary, Vancouver, Edmonton a few times. They trained me to sell and I excelled at it. I really did. That's when SaskTel picked me up. I was top salesman four or five times a year for the company. I have always been able to communicate with my customers. Make them feel at ease when I talk with them. Identify what they need and really just work with them.

When asked about where his career is going now:

I want to go back into school. I want to be a cook but is it going to pay the bills? I want to go to Saskatoon Business College, business management. I want to go to SIIT [Saskatchewan Indian Institute of Technologies]. I want to get into some trades. I got all these trade skills. I think my first step right now is just to get my grade twelve. I've got my partial grade twelve and just get into something.

Another adult with FASD is continuing to work on her education:

It's good. I've been going everyday. I like my math and everything. I ask for extra homework. I have my Grade 12 already so it's just upgrading my math and my writing. That's all I'm doing. In Regina at SWAP [Street Workers' Advocacy

Project]. There's two classes so that's where I go to school from eight to three, I mean from ten to three.

The adult signed up for these classes on her own without help from her mentor and she obviously enjoys attending and is proud of it.

I needed something to do and they wanted to send me back to Sask Abilities in Regina. The thing with that, they held my check last month because I went to school instead of going to work. I was supposed to start work on November fifth but I didn't because I went to school by November sixth/seventh. My worker (social worker) found out and they said, "Well you made a promise." I said, "Did I sign a piece of paper? Did you see me sign a piece of paper?" So I chose school over work. So I said, "You can't hold my check like that, just because I made my choice." So rent was late. I want to get a better education. The thing is with these workers, they always think they can run my life but I don't like that. I made my own choice and I'm happy with the choice I made. I said, "If you don't like it, that's... You don't like it but I love it!" But they gave me back my rent check.

When asked what she liked about the SWAP program:

It's kind of a laid-back school. No pressure. No tests or anything or pop quizzes or anything. Just come as you go, I guess. But I'm there everyday but some people don't even practically show up. Every time there is a check day hardly anyone shows up but I'm there everyday. I'm very punctual and I'm committed to stuff.

This adult is taking one day at a time and does not have any future plans for education or employment.

Another adult has worked part-time and this seemed to work well for him:

I am working at Crocus whenever I can get down there. You can go there whenever you want. In the winter you shovel snow or move people. And summertime, we landscape, like raking leaves or moving people. I find it's a good job because they don't pressure you to come in everyday. Just more work at your own pace. That works for a lot of different people.

Crocus Coop is a support organization for people with mental health disabilities in Saskatoon. It works toward social integration of people by giving them a place to learn, work and heal. This adult's mentor helped him with his work at Crocus:

He has me work on a routine. When I am working he gets me to work.

Another adult with a new-born baby plans to go for upgrading and eventually find a career in social work:

I do upgrading in January for three classes and they said it is only going to take a couple of months. And then I am going to go to University because I want to become a social worker because they suck at their jobs. Just kidding. No, just some of them... I have been wanting to do it since I was like in Grade Eight. I don't know why. I just stuck with it, how many years later.

She is planning to attend Saskatchewan Indian Institute of Technologies and her mentor has been helping her with the arrangements:

She's been taking me to, like, interviews. Program meetings, SIIT. She helps me a lot.

Another adult is currently looking for work but he admits that his mentor is willing to help him but often he declines that help.

Do you want me to go help you deliver resumes? [his mentor asks] No, I can get (my girlfriend) to help me do it and then I don't really do it. There are always different things to do like getting involved with family and friends.

He recalls two past work placements. He talks of these with fondness and enjoyment.

He is interested in trying to get employed at these places. The first placement was at the Core Neighborhood Youth Coop (CNYC) which is an alternative education and skill building program in Saskatoon for marginalized youth:

Carpentry, used to do carpentry at the CNYC. It was really fun there so trying to get the information, see if I can still work there at least for five months or so, so I can get baby formula and all that.

He liked the work environment at the CNYC and the feeling of being productive:

Always having company. Always being busy instead of wandering around the streets. Used my hands a lot, fixing. Used to fix bikes over there too. They had a lot of things for me to do over there. I could just drop off a resume over there.

The second placement, the young adult with FASD mentioned was a work experience that he did while taking a high school Life Skills Work Study Program (LSWS) in Saskatoon. Although he was “kicked out” of that school, he was appreciative of the training he had received at his work placement at Canadian Tire Auto Body Shop:

Taught me to take off the wheel cover, change the oil. Janitor thing too, cleaning up, sweeping the floors, getting the water off. One of the teachers over there (LSWS) they got me assigned to do that stuff.

Staff Perspectives

Staff members at the CUMFI Wellness Center recognize that preparing an adult for employment is a work in progress. Mentors are more concerned with helping their adults set realistic goals than forcing them into the workplace before they are ready. If an adult does want to work, they would try to determine the capacity that adult is able to manage. Volunteer work, work readiness programs and part-time or casual work are considered. In many cases, adults have enough on their plates. For example, they may be in training, attending probation, counseling services, addiction services, anger management classes and/or parenting their children.

When they are interested in working, what’s the capacity for this person to work? Can they work full-time? Can they work four hours a day? Two hours a day?

other issues to overcome first.

Mentors report that many of their adults are not ready for employment. They have issues to deal with such as counseling for anger management, abuse and addictions.

The individual has needs first before they can get employed. Some of them have a history of foster care and stuff like that, abuse one way or another. Because of their disability they are very vulnerable so they are more like followers than leaders. I find with that - there are things you need to deal with like life skills. There are several things: some might have addictions, some might have anger issues.

“To even try and think of them being employed” these prior issues would have to be dealt with.

A lot of them were in gangs, addiction, foster care, abusive relationships. Now I think they are just starting to heal again. Going through addictions or any AA meetings or people, it takes a community to support one individual. The mentor yes, helps but they might have a PALs person. If they have kids, they might have a Kids First person. If they are in jail, they have a PO worker. They have programs that they go to.

Another mentor added:

It's their self-esteem. They have many other issues. There are many barriers they have to work through before you can even think of employment. Anger. Some of them have been in the welfare system for so many years. Some of them were in foster care for so many years and there is no stability in their life, no supports in place so it just takes a community. It takes so many supports to try and help this one individual.

Staff members noticed that adult's inner issues were one of the main challenges to being ready for employment. Mentors offer support, understanding and guidance when their adults confide in them. On a regular basis, adults can access a counselor who comes to

the CUMFI Wellness Centre. Having a counselor they can easily access in a setting they are comfortable in is a great advantage for the adults with FASD.

They struggle with the past, what happened to them before so we have to try to get counseling for them to deal with these issues.

Having realistic expectations is essential when working with individuals with FASD. Success needs to be defined on an individual basis. If a adult is not ready for work, then the mentor will work with them to overcome barriers, build their confidence and practice daily living skills. The mentor will continue to encourage the adult with FASD towards setting and achieving personal goals.

There are times that work is just too overwhelming for them. There are times when I have tried to set up work for people and before it happens the person melts down. It is almost too much at times for certain people to expect them to work a normal job.

finding work.

Mentors help their adults with resumes and they help them to get connected with other services such as the Partners in Employment, SIAST Way to Work, Saskatchewan Abilities or Value Village. Adults are often assessed by the Saskatchewan Abilities Council and this detailed assessment is valuable to finding out where the adult is at. Mentors also help prepare their adults for interviews, “you sort of have to sell yourself and if you don’t have much self-esteem it’s hard to do that.” Mentors help to build up their adult’s self-esteem.

developing a routine.

One mentor talked about the issue of their adults getting to work and being on time. Mentors often drive their adults to work at least at first:

They just have a hard time struggling to get into their employment. I always need to remind them to wake up to go to work. With my adults, I give them wake-up calls initially until a routine is established. They have to get in a routine of getting there and doing the job and it is just a matter of routine. They can do the job once they are trained and they are very good employees and very productive. It's the time management they need, the structure and scheduling.

maintaining employment.

People with FASD often work for awhile but do not seem to be able to maintain this over the long term. Mentors talked about this trend and some possible reasons for it:

I think my observation would be that sometimes people can work full-time for a certain period of time but not ongoing over the long-term. It's more of a pattern. They can hold that job for three months or something but just don't seem able to sustain it in the long term. Sometimes it causes so much stress in a person's life so things fall off the rails. Need to have the right balance there because it is not successful if somebody else is deciding that. I think we don't recognize how hard people are working. It seems to take three times the self-discipline, the concentration, all of that, for persons with FASD to do all they have to do to keep a job. I think this is where the stress comes. If you don't remember things easily, you're not good at generalizing where you should do this. You are not treated very respectfully by the employer, your co-workers who don't understand why you are not on top of everything. I just think that people are working very, very hard in ways we cannot even imagine.

This staff member is aware that of the incredible effort it takes from adults to be employed.

Another trend that was mentioned was that the adults with FASD lose focus – they become bored, restless or lose their motivation to work. Mentors see adults quitting their jobs for a variety of reasons.

One was the season changes, summer is coming. Another one was “I don't want to do this anymore.” The reasons they give are reasons that their bosses wouldn't accept but when you look at it that way you can't force them not to quit.

Another mentor added:

A lot of my adults, they kind of jump around. They have a hard time to focus on one thing and one task and doing all steps necessary for that one task. A lot of my adults say they want a job then a few days later they want to go back to school then a few days later they are good with just staying on social assistance so a lot of that is motivation.

Sometimes adults grew frustrated if the job became too hard. A mentor talks about the difficulty of an adult starting something and not finishing it, “they come and tell you, but not the employer or they won’t tell the school.”

getting fired.

A mentor said that if they do get fired, “there is going to be no ridicule from us. We are going to ask them what happened and not make them feel like they did something wrong.” Mentors are aware that their adults have had a lot of setbacks in their lives and are very good at “beating themselves up” so they always try to be positive with them even when they are fired. Here are a few possible reasons that adults with FASD might get fired:

They get the job but once they are there - their impulsive behavior, they lose the job. They lack the basic skills to hold a job down. Drinking coffee all day and getting hyper on coffee, getting fired for horsing around, talking to people on their cell phones at work - the common sense things that most of us would know.

need for employer training in FASD.

Mentors help to educate employers on FASD.

Not having them feel like they are making the wrong decision employing them because they can do everything we can do, it just might take more effort on their part. Just educating them that he has FASD and the things that come with it, if they have no idea. We have this booklet we are giving from Partners of

Employment for employers. It kind of gives a run-down on FASD and the struggles that they might have.

Adults can have difficulties on the job if they have to relearn their job every single morning.

Or people who are taught to do this over here but then another day they are moved to a different location and they are supposed to do the same thing but can't generalize their learning from one location or situation to the next. And that generalization, learning something in one place and then applying it in another or taking people very literally, maybe afraid to ask questions. A whole lifetime of being "dumb" and just trying to go along with things and "making stuff up" instead of asking questions.

A mentor talks about "finding an employer who understands FASD and what it is all about."

If they are late, it is not because they want to be, it is how their brain works. It is adapting, being understandable. The natural consequences with FASD don't work. You're late, they need the flexibility to know that they might be late but don't fire them. If they have been late five or ten times that is the nature of the disability. The natural consequences don't really work in disciplining them.

Summary of Education and Employment Issues

Most of the adults are not actively pursuing employment at this current time. Rather they are taking classes, raising a child or trying to improve their lives by staying sober. They are motivated to self-improvement and have future plans. The adults with FASD often have other issues to overcome such as trauma from their past, addictions and housing issues before they can be employable. To support adults with FASD, we must accept where they are at and help them to set goals for

Sometimes mentors feel that the adults don't set realistic goals. They also see the adults having difficulty staying on a course of action. At times the adults seem to be

optimistic about the future plans. It is difficult to know which side to be on- the side of realism or the side of dreams. I understand the common sense somewhat cautious approach of some staff who have witnessed lots of failure in adults plans. They wish for the adults to pursue reachable, short-term goals. At the same time, I would never want to discount anyone's goals and plans no matter how out of reach they may seem at the time. To do so, I believe would discount the individual with FASDs potential but even more so, their humanity.

Both adults and staff recognize that the need for structure at workplace and assistance from mentors in finding and maintaining employment. The need to understand and education adults about their FASD and their employers was a common theme.

Money Management.

Adults Perspectives

Money management is often a difficult situation for adults with FASD. This was an area of difficulty identified by the participants in this study. Some adults handle their own finances:

I don't want anyone holding my money for me saying "Look here, I am only going to give you so much. We're holding the rest 'cause you need it for that."

Other adults welcome help with their finances:

Pretty much that is (the program coordinator's) job. She takes care of the bills and that for us. She helps us a lot.

An adult had the staff at CUMFI hold some of her money but now that she has moved to Regina she is managing her own finances.

I was starting to give them forty to fifty dollars when I got my cheque but ever since I moved, I manage my own money now. I buy groceries and stuff. I have my auntie who helps me buy groceries. I was on trustee in Saskatoon but when I moved to Regina they wanted to put me back on trustee but I said, “no” so I’m not on trustee. I manage my own money.

Some adults want to manage their own money and are indignant if asked if they have a mentor to help them.

Other adults appreciate help with their money matters:

They took me grocery shopping when I was at the Infinity House and stuff. And whenever I needed help buying anything, I’d go up to them and say, “Hey, I want to buy this.” And we’d go right away. We’d look at price options. They’re good with that.

When the following adult was living in Saskatoon, she often gave the staff at CUMFI some of her money for safe keeping:

Started this thing with people at CUMFI. I gave them half my money because people would always find out when I would get money and they would be so called ‘all over me’ and chasing me down. “You owe me this, and you owe me this” because they knew when I got my check. They don’t even know me. They’re just people on the street that are after my money. They act all nicey nicey and then bang - when I got money they start chasing me down saying, I owe them this and I owe them that. And I say, “You guys are the ones that used me for my money, I was just trying to be nice. They’re just using me. That’s all I know. ... They’re just street people who are druggies who want a little bit of cash. “Help me out with this”. And I give them a toonie. “Oh, give me another dollar – I got to get back” so I give them a little bit – three bucks and then they come back and they ask me for more money. “Do you have five bucks I can borrow?” I said, “No, I’m out, I’m tapped” and then I walk away but then they yell at you. “You owe me something and such.” That’s why I always have to come here on payday. Ya and I don’t like it.

The adult was visibly distressed and did not want to keep talking about the money problem on the streets. It was obvious that she didn't feel safe with walking around with money.

Another adult also gets help from his mentor in money matters as well as a trustee at the Salvation Army who pays his bills:

Well if I get extra money for things then (my mentor) will hold onto it. Like for shoes or hygiene supplies. He tries to help me budget.

The adult says that he is okay with this support. He finds it difficult to keep his money:

I spend it fast, don't really budget too good. I buy tobacco products or junk food, pizza.

Many adults had difficulty with having enough funds to buy groceries. Sometimes these adults have to access the Food Bank. One of these adults had social services increase her food voucher and is able to eat better now:

They [social service] were only giving us seventy five dollars for a food voucher every two weeks but then we talked with a trustee and we told them that seventy five dollars doesn't go very far for two weeks so we asked them if we could put it up to one hundred fifty dollars and actually it's a lot better now. Enough for two weeks at least.

Some of the adults access the Food Bank when they need to.

Staff Perspectives

Mentors talked about the issues their adults had with money management as two-fold. First, many adults with FASD do not have a lot of money as they are on social welfare. Secondly, managing their money effectively and not spending it impulsively is a common issue for the adults they work with who have FASD. The mentors talked about another adult who felt too safe with money and who waved it around, was jumped and his money

stolen. He had been showing off the pay he had just received and he ended up in the hospital.

lack of funds.

Mentors are sympathetic about their adult's money problems in that they recognize that it is very difficult to budget when you don't have much money.

The first challenge is the majority of them are on social services and the money that they receive is like so, it's like way under poverty, and so they have other habits such as smoking. That is one big thing that they do spend money when they have it because normally they don't have. Of course you are going to buy the little things that you may need but spur of the moment - it burns a hole in everybody's pockets. The majority of them are on social services and they don't really have that much money. They have to get their toiletries, groceries, their laundry money. Food is an issue too, in most cases you end up taking them to the food bank.

poor money management.

When adults do have money, they often do not have it for long. "As far as money goes, if they need stuff, the money is gone within a day almost. They don't budget." At an adult's request, staff will take some of their money and lock it in a filing cabinet to help their adult budget. For example:

If they have money for the weekend and they don't want to have it, we just lock it away for them, label it and do a receipt kind of thing.

The problem of adults spending their money on addictions was brought up by a number of the mentors.

Money, the root of all evil and it's no different for them. A lot of times they only keep a job until they get a paycheck, then they start missing. Of course, there is the addiction, if they have extra money they spend it on other things than the necessities of life.

Another mentor said:

When my adults have loose money like twenty or thirty dollars, they have a temptation to use drugs or alcohol. The likelihood of that happening is almost one hundred percent. It is really being cognizant about what their money rhythm is so that you are available to help with planning, spending and ensure necessities – rent, groceries, utilities are paid first. You know one fellow has a real addictions problem if he has any money. He gets money once a week and he makes sure that we are there to take him shopping and make sure he spends it all so that he doesn't have any more than like two dollars. And I mean, he goes along with this, it is not like we force him to do it. He explains it himself, "If I have money, I just think about drinking and I can't get it out of my mind."

A mentor said that a challenge his adults had with money management was:

Buying stuff that they don't really need instead of stuff they can use, like also with addictions. You have to be kind of aggressive when they have money and make sure they spend it just so that they're not running around doing 'who knows what' because this is a dangerous part of the neighborhood. Even being frivolous with their money - taking it out and flashing it, being reckless with it. Just to make sure they spend it on things that they need - a winter jacket. I just took (my adult) out there for a winter jacket and some shoes. He normally wouldn't have bought that if I didn't go with him. He would have gone out and – I don't know what he would have did- but he would have probably been missing for a couple of days and then came back and he would have given me a long story about what happened.

Two mentors noted the generosity of the adults with FASD they mentor. They mentioned how their clients will hand out cigarettes to other clients and how they buy their mentors gifts even though they have limited finances.

conflict.

Mentors talked about the conflict they have with helping adults manage their money. The adults with FASD are often not willing to receive help in managing their finances and if they are willing, they often are dissatisfied. "Well you can't tell us what to do,"

was what one staff member reported her adult saying when she tried to intervene with money matters.

You ask them - What are you going to do with your money? “Oh, we are going to go out for supper and we are going to do this and that.” Well what about your toiletries, do you need pads and shampoo? Do you need aftershave and stuff? “Oh ya, we got some.” How much do you have at home? “Well you can’t tell us what to do!” But you need that stuff. “We have no money for this.” You have to budget for your money. What’s so sad is they end up getting food vouchers because of that situation through their trustees and stuff like that and that’s when they are allotted their money for maybe tobacco and whatever they need to buy. And as far as money goes if they need stuff, the money is gone within a day almost. They don’t budget. They don’t know how to budget.

Another mentor said:

I mean you deal with the same thing, week after week. You do that planning so that they have this much for cigarettes or food and they just don’t remember, don’t keep it central enough in their mind. What about food? What does it feel like when I don’t have any food? What does it feel like when I don’t have a cigarette? The current gratification is really difficult, I think.

Staff members have seen conflict when their adults borrow money and cannot pay it back.

Lots of difficulties over making an agreement like buying things or loaning things on time. I am going to buy this from you and give you twenty dollars on Friday and on Friday the twenty dollars isn’t there. Meanwhile they’ve taken possession of the item. They are always borrowing, lending and making deals.

trustee.

Staff often set their adults up with a trustee through the Salvation Army or Crisis House.

And that works very well if the adult only gets X amount of money. They get food vouchers that they can only spend on food plus they have spending allowance. That works well.

Mentors find that it works better for their adult to have a trustee so that they do not have to be in that role. It helps them to have a relationship with their adult with less conflict.

A lot of my guys are on trustee. They have a trustee at Salvation Army and I think it's a good idea. I kind of stray around the topic of money because when you're dealing with money, you get a whole different other issues. They tend to have ill feelings towards you if you are dealing with their money or tell them how to spend their money. So dealing with the trustee - they give them a set amount of money and they get all their bills paid for and then the money they get, they will be able to spend it for groceries or clothes or whatever.

grocery shopping.

Taking adults to buy groceries is a common support given to the adults with FASD at the CUMFI Wellness Centre.

We help them with grocery shopping, by encouraging them to make a list of needs. We take them out to do the shopping and to pick up the healthy choices, bills and bus passes to budget their money with the groceries that they need from month to month. And the bills that need to be paid.

One staff member stressed the importance of food to people with FASD.

The number one thing I find with FASD is food. Food. They need to eat all the time and that is one thing I noticed. Food is always an issue because they don't budget well even though you try. And the more they eat the better, you know? The better they do, having five little meals a day. When we're not available they tend to not buy as much groceries or not even buy groceries sometimes until we assist or accompany them. We always know what dates when they get their money.

She said that food is always an issue because they don't eat enough. Individuals with FASD may forget to eat as their sensory system is not giving them the cues that they are

hungry. Parents and caregivers have reported it two ways – individuals with FASD who forget to eat or who do not gage when they are full. Staff at the Wellness Centre, find that they need to remind the adults with FASD to eat and buy groceries. At the Wellness Centre, mentors will make their adults a soup and sandwich. There is also fruit available from the Good Food Box that adults can eat.

Encouraging their adult's to purchase healthy foods is an important role the mentors play.

Sometimes they are a little hesitant to try new things but then at least we get them vegetables. If they don't want to buy vegetables then at least get them some soup or stew with vegetables. Try new ways for them to at least get their nutrients through that and then slowly they'll come along. I've got this guy - nothing but chips and pop the first couple of times. He really didn't want to get anything else other than that. That is what he ate - chips and pop and he'd grab a couple of steaks and that's all he ate. Just slowly, gradually getting him to try this. Giving him some noodles and Kraft dinner, just more healthy decisions. A little more healthy than just chips and pop and junk food.

Summary of Money Management Issues

Most of the adults felt the need to have help in their money management. For example, many of them have volunteered to keep some of their money with staff for safekeeping for a period of time and also appreciate help with shopping. Sometimes however, the adults do not want interference in their money affairs and wish to handle things on their own.

The staff understood the difficulties for the adults to manage their money. Staff saw the need in helping the adults with FASD buy necessary items such as healthy food, winter clothes and toiletries. Both adults and staff talked about the importance of the

adults with FASD spending their money when they received it to help prevent it from being spent on addictions.

Grocery shopping was seen as an important area for help in by both adults and staff. Both staff and adults agreed that lack of funds and difficulty managing it was one of the serious issues. Both sides portrayed that this area could be a source of conflict between them. Staff recognized this by often setting up their clients with a trustee to reduce friction.

Accessing Services

Adults Perspectives

social services.

Adults find out about services from their mentors that they would not have known about. One adult was able to get some work clothing provided:

The work clothing supplements. Supposedly you get through social services which I didn't know you could.

This adult is on assistance. Her mentor gives her rides to social services: "I had to go there a couple of times." Her mentor often helps with forms as well:

She helped me fax over change of circumstance forms, move forms and other forms kind of like that. That's the faxing, there's a lot of it.

health care/mental health.

An adult gets help from her mentor to go to her doctor's appointments:

But I go to my doctors for scheduled routine birth control every three months. So they [the CUMFI Wellness mentors] go with me for that. They always drive me there but the thing is I don't like needles so I'm kind of scared to go and I try to push it off but [my mentor] says, "Come on, let's go. It's not that bad."

Another adult suffers from mental health issues:

My schizophrenia was really bugging me so I had to go there [to the hospital]. I was diagnosed with it when I was fourteen. It's on and off [gets worse and then better].

He was referring to when he was in a treatment centre in the past. During his second interview, while incarcerated he talks about his schizophrenia:

I've been seeing things a bit but not as much. It was gone away for a long time but it came back again. I see shadows or people. I hear people calling my name and stuff like that. My little girl talks to me, she was a stillborn. It's kind of scary because she is psychic. I can handle it well. I tell them to go away. Sometimes they go away, sometimes they don't. I turn my music loud, drown them out. Try to get rid of them the best way I can, the healthiest way I can.

He distinguishes between the good voices and the bad voices. The good ones are:

An angel would tell me, "Don't worry, Daddy, you'll get out. Just be calm" and all that "Take it easy, cool down," and good stuff like that.

The bad voices:

They tell me go back to small dorm and go kill all those guys for what they did to me or if I see someone walking around with a knife or a gun, they say, "Go take it from him." But I don't listen to the bad, you know. It is hard.

This adult feels a lot of emotional upheaval due to his illness. He tries to be positive about it but sometimes it pushes him over the edge. He recently spent some time in a mental health clinic:

Up and down, happy sad. Want to die. Don't want to die. But right now I'm just kind of upset about housing issues and stuff. But still I'm happy on the inside but I guess mad on the outside.

The adult admits to being suicidal when he was little but says that he grew out of it.

I still feel like I want to die sometimes but I won't go for it – actually do it because it would be a spiritual death you know and I won't come back. Where if it was a physical death, I could come back. You know, I don't want to die. I love my life to death. I have a girlfriend. I have a good family. I want to live.

This adult said this while he was incarcerated and in lockdown. His effort to be positive was evident. When asked what caused him to be suicidal when he was a kid he answered: “The voices. The voices and being in and out of foster care and stuff. Just the stress.”

It was notable that all of the candidates that I interviewed were adopted or in foster care during their life. The psycho-social stress of being in foster care must complicate the difficulties of already living with a neurological impairment. I asked this adult, “I thought your parents adopted you?”

Once they couldn't handle me, they just put me in foster care. There was this one lady by the name of [the adult's foster parent] was in White Rock and then there was another lady in White Rock - two in White Rock I think. There was another one in Vancouver so I think I was in three or four ones in Vancouver.

“How old were you when they couldn't handle you?” I asked:

Fourteen, I think I was fourteen the first time. Then they let me come back when I was sixteen. We fought again and they couldn't handle me and they kicked me out when I was sixteen.

His mentor helps him to his appointments and reminds him to take his medication:

He gets me to my appointments. He teaches me a little bit about FAS and my other illness. Med awareness. He says, “Well if you miss your med, then this will happen.” He tells me about my medication. He takes me out for coffee once in awhile or to movies. He is part of my support team.

other services.

Staff at the Wellness Centre helped a young adult to participate in a talking circle about his troubled past with other youth. He felt that it benefitted him:

They find all these programs for me to go to. I was supposed to be doing a job interview, some type of interview thing with Mount Royal. They took me to a little meeting where some teenagers were talking about their lives and how hard it is and then they can speak it out to others. That's what I had to do. Talk about gangs and how I lived and how hard it is to struggle when you are on your own. I found that kind of fun. It was good to say it 'cause people can understand more why you join a gang because if they lived the life we used to live.

Mount Royal Collegiate is a high school and trade centre in Saskatoon.

addictions.

Substance abuse issues have affected many of the adults at the CUMFI Wellness Centre. It seems like some of them do better for awhile and then their addictions get worse again.

Marijuana, back when I was younger. I loved to get high. It was fun, it was very fun. Friends would get together and we could have a blast until I started stealing for what I wanted. I was a young offender at the time and I learned from that. I said, "You know what? This isn't fun anymore." I quit cold-turkey. And I used to drink a few times, I was a kid. It was never a problem. In 2000-02 I started drinking. I said, "This is fun." Have a drink at a barbeque, at home and shut 'er down. It's starting to get boring. It's starting to become priority and I don't like it. It's time for me to quit right away. Oh ya, I come over here [Wellness Centre] sometimes and I am hung over. You can see it in my eyes that I am hungover. They'll say, "[the adult's name] can I talk to you?" "You know what? I had a good time last night and you are probably the last person I want to talk to right now. I'm not in the mood." And she'll say, "I appreciate the honesty, we'll talk about it tomorrow then." So I just hang out at the office and just have coffee. Talk to my friends.

When asked if he felt the staff was willing to take him as he is, and if they will give him advice he answered:

They've helped me. When I ask for help, they help me. But when they offer it, I'll say, "Look if I need the help, I will come to you. I am 26 years old. I'm not a young kid anymore. If I had a drink, I don't want to feel like I have done something wrong. I went home and I slept and I came here." A couple of months ago, I asked for help. Well four months ago. Ya, I mean, the support was there. They helped me do the referrals. They helped me get the rides to and from the addictions services and the treatment program. I was ready to enter at the time and they set me up at a housing situation with CUMFI. The same program I am on the waiting list for now. I was actually scheduled to move in. I thought at the time, "I am not ready to quit drinking, I still enjoy it." And I screwed everything up, I went to Vancouver actually and I ended up partying in Vancouver for a month. And I um, the treatment program I was scheduled to be put into, never happened. The housing program I was scheduled to be put into, never happened. I don't feel scrutinized for my addiction at all. I don't feel judged. I feel that when I am ready...

It seems like there is a real conflict with adults with FASD wanting to be independent on one hand and needing support on the other hand. It is a balance and not easy to achieve. Most of the adults in this study expressed their desire for independence and also expressed their appreciation for help as well.

Another adult talked about a living situation where he had to quit using substances:

I have been clean and sober since June. I was put in the Salvation Army and they had no drug or alcohol policy and when I moved in there, I quit everything.

This adult said that addictions were a big problem in his past. He thinks he got into drugs and alcohol when he was sixteen. The adult was twenty-seven when I interviewed him. He said 'peer pressure' was a factor in him starting.

Staff Perspectives

A big role that the CUMFI Wellness Centre provides is to connect their adults with supports and services. One mentor said, “It just takes so many people just to help that one person.”

For instance with a mother, she had a Pals worker, she had a Kids First worker. She had a social worker, a family services worker. She had a counselor at mental health. She was taking upgrading in schooling. She was taking parenting classes. She was taking classes at White Buffalo Youth Lodge. She was taking self-esteem, she was taking anger management.

Mentors network with the larger community to coordinate and build supports for their adults.

I think that mentoring adds to the cost effectiveness of all of the services in the community. Without mentorship there is a group of people (people with FASD) who can't access services effectively. We try not to duplicate services but rather assist people to make better use of the services that are out there already.

According to a mentor:

I think we are kind of the gateway to a lot of that (assessing services) because sometimes these adults don't even know what assistance is or don't know what social services is or they don't know what a psychiatrist is so we are the ones to bring those things to the table. For example, someone who is sleeping all day, you say, “Do you want to see your psychiatrist? Do you want to see your doctor?” We always try to connect people to services beyond us that can help them. If you are feeling sick, go to the doctor. If they are depressed, how about we try to see the psychiatrist? If they are suicidal, how about we go to the emergency room?

social services.

Adults are helped with navigating the social support system which is a great help.

“We work a lot with social services.”

People have often been turned down for services and I don't know exactly what that's all about. I think in a lot of cases it's because they are in a situation that hasn't been described well enough. People who provide services: Often – this is my mandate and ABC - do all these things fit for you? And if there is one question answered wrong or something or there is lots of subtleties in questions. They may just be told, "You don't qualify" or "We can't help you." Whereas if we call and revisit it. They need advocacy and they need good communication and I'd like to think it's the good communication that is lacking. But I think lots of times it just simplifies service provider's lives to say "no" rather than... People don't often have the really helpful way of doing things. But really in all the service providers that we've worked with, I think we've really helped people get services that they haven't had in the past. But it seems with some advocacy, service providers are really great.

If needed, mentors help the adults to access social services by making appointments, providing rides, helping them fill out paperwork and advocating for them. Mentors act as a middle man to explain the system. This is extremely useful. For example, an adult may not know that they qualify for a free leisure pass from social services or that they can apply for a clothing allowance if they are starting a new job.

A lot of our adults don't know that with social services you get transportation. You get a bus pass. You get a free leisure pass. A lot of them don't know that. That's five hundred dollars for me to go buy. We let them know, this is expensive. This is great to have. You can use it at any one of the services out there, leisure activity services. Just hooking them up with that and making sure they use it. Sometimes we have to go with them to make sure they use it.

health.

Helping adults to look after their health is another support that mentors can provide. Some adults need help booking appointments and remembering to take care of their health needs. Others do a good job of these things on their own. It is important to keep in mind that adults have varying needs and that adults are treated on an individual basis.

Westside clinic, they know where that is, we book appointments for them. Some of them have such a hard time explaining - have a hard time with their speech. They phone us and ask if we can book an appointment for them or if we are the doctor's office, book an appointment for them.

At times, mentors do a lot more than just helping their adults make and arrive at appointments. Mentors can even attend doctor's appointments with their adults and have a large role in helping them manage their medications and health needs.

I have diabetes adults and I like to take them for check-ups on glucose levels especially if they're going to get their needles done early in the morning. I pick them up and take them to get their blood work done.

Another mentor adds:

Even with healthcare, setting them up with doctor appointments, making sure they keep their appointments and going with them when they go. Hearing what the doctor says because sometimes they might just nod and think that they get it. Afterwards, we can go over it with them and just revisit what the doctor said. Then check up on them regularly to make sure, "Are you taking your medication? Make sure you are taking your medication."

This mentor went on to say that he reminded his adult about taking his medication because of the problem that many adults have with their memory.

Then just checking up on him, I might start asking him, "How much did you take?" Then see if he says one and a half, see if he gets it. Then, I know I can check up on him every three days, or whatever.

Adults are also encouraged to use the Good Food Box, a Child Hunger Education Program which enables them to get local produce for a reasonable price to encourage healthy eating habits. A quit smoking session has been offered in the building as well as cooking classes.

They have a community kitchen that's run downstairs here where the adults get to participate and they teach them how to make something that's healthy and easy for them to just whip up. They make it with them and then they get a meal that they get to take home.

Mentors also engage in conversations about birth control and safe sex practices with some of their adults. A mentor may take an adult to doctor's appointments for birth control or provide their adults with condoms.

other services.

The mentors also help connect their adults with an extensive variety of other services:

We also deal with different organizations that deal with perhaps parenting classes. We do send adults to treatment centers for addictions. They do take classes as well for dealing with addiction, like relapse, prevention, anger management. Anger is also a big issue. Seems like all of them are really big issues. And then there are always some who like to go into a cultural/traditional setting. We do go to sweats. I've gone with another mentor, we have taken adults to a sweat on a Thursday night. The ones that we did take seemed to respond quite well to elders. We also have elders that come in and talk with the adults. Feels like a bond with an elder. With eldership, there is a certain respect so it helps them to reveal a lot of stuff to the elders.

Many adults are also connected with the Saskatoon Food Bank. With their meager budgets and at times, financial mismanagement, having enough food can be an issue.

The food bank also offers free counseling which some of the adults take advantage of.

White Buffalo Youth Lodge in Saskatoon is another support that adults are sometimes connected with:

The White Buffalo Youth Lodge, they have been great with setting them up with programming, especially a lot with our parents that we have. They have parenting classes. One called "Strengthening Our Spirit" where its twelve weeks and they get a certificate. It's helped a lot of our adults get back their kids because it gives

them a certificate that is recognized by Child Family Services, so they learned parenting skills.

Making crafts and playing basketball are other types of activities available at the White Buffalo Youth Lodge. Mentors often go with their adults initially until they get comfortable in the environment.

The CUMFI Wellness Centre is also housed in the same building as the Central Urban Métis Federation Incorporated and a variety of services are available in the building for adults with a First Nations background.

For income tax reasons - they come to us and ask for assistance. Actually our office here has a free service for income tax purposes so they help them out with tax issues and the treaty cards if they are needed. We have access here too and immunization, they have access.

mental health.

Helping adult's access services in mental health is a sometimes necessary and important intervention.

A couple of my adults, they have severe mental illness. Just setting them up with the right services, how do they go about it? They'd never even attempt to go see a doctor about some of the things. One of my adults has schizophrenia, and he goes to see a psychiatrist, and he gets medication for it. He would never have done that had it not been set up for him. So, just making sure he goes to it regularly; every three months. Psychiatrist. Make sure he's taking his medication and make sure he knows what it's for.

The subject of suicide was addressed by one of the mentors at the CUMFI Wellness Centre:

We've seen a few times for suicide, where they phone us and you know, so we just set them up with mobile crisis. Or just even talking to them on the phone, making sure that they have supervision while they're going through that mood,

and then setting them up quickly with the doctor's appointment after that. It would be useless to take them to a psychiatrist, because they're having suicidal thoughts. Set up a psychiatrist appointment – a month and a half later. Oh, it's appointment time. Well, they're not feeling that way anymore. So, for a lot of them, we just take them to the doctor. They see a lot more cases of depression than psychiatrists, just because it's a lot more accessible. We've got to go away for two hours and go to the doctor, but hey, going to be alive tomorrow, anyway.

addictions.

Many of the adults at the CUMFI Wellness Centre have addictions.

I think in the last year, we've sent about four adults to treatment. Just making sure that they go to the right treatment center - that's going to give them all the tools and skills that they need. There's a big one – that's been the Cree Nations Treatment Haven. They have a program especially for people with FASD. We've worked with them, and they've been great. We phone them, and try to get them in as soon as possible. There's even talk about having them set aside an ongoing spot for us. Just one spot, a "just in case" type of thing because treatment is a big deal. A lot of our adults were involved sometime with addiction.

Cree Nations Treatment Haven is on the Ahtahkakoop Indian Reserve in Saskatchewan.

It uses the "Life Process" model of addiction. The program uses a client-directed outcome therapy approach which encourages adults to develop individualized treatment plans based on their own needs, situations, values and beliefs.

One of the mentors at the CUMFI Wellness Centre is also trained as a substance abuse counselor and he is in the process of developing a treatment program that can be used with adults with FASD. Addictions treatment programs are often based on cognitive behavior therapy and these programs can be ineffective for individuals with cognitive disabilities. An important consideration when deciding to use cognitive therapy would be to determine if the adult is able to learn from consequences. Fetal alcohol spectrum disorder causes impairment to the executive function which is used to do

mental processes of a higher order like planning and problem solving (Wagner, 2009). This makes using cognitive therapy with individuals with FASD problematic.

Summary of Accessing Services

Adults seemed to value the help staff gave them in accessing services. A few of them mentioned, not knowing about services that were available to them like the free diapers or clothing work supplements. In addition, they seemed to appreciate the support of having a staff member not only help them get to appointments but often attend with them as a support.

Staff members were quite busy helping their clients access services and saw this is an essential support that they could provide. Staff noticed that their help in communicating and advocating was necessary at times to receive proper supports for the adults. They saw their role of coordinated services as cost effective. The mentorship was able to provide individualized support to the adults.

Adults want the opportunity to access services but they also wish to be able to refuse help. They do not want to be forced into things and yet appreciate that it is available to them if they decide on their own terms. From staff perspectives, there are a lot of basic coping and living skills that some adults needed help in such as taking their medication or birth control properly.

Leisure Activities

Adult Perspectives

Adults enjoy a variety of leisure activities. One adult likes to go for walks and read books. Another adult enjoys sports:

Skateboarding, snowboarding, basketball, sometimes soccer. I grew up doing that in the foster home.

This adult also writes lyrics for songs and is interested in getting into rapping:

I also wanted to become a big rapper and that. Put it on a CD. I just finished meeting a DJ a couple of weeks ago, talking to him on Facebook and that. It's been pretty good. He has his own CD he made. Listened to it, pretty good.

He writes lyrics about:

Life on the streets and how people are changing their ways and how life was back in the day and why did we all change for a reason 'cause I guess we just wanted that intention. That courage to push ourselves to do things we never tried before.... Why they're leaving it. Leaving it behind because people say the past is always causing the problems for you. Look to the future and you will have bigger dreams and courage to push yourself to that.

The adult talks about leisure activities he does at the CUFMI Wellness Centre: "Well I play pool here. That's pretty much it and talking to people."

Another adult likes athletic pursuits as well as art:

What I am doing right now, is I am taking walks. I walk a lot. I could take the bus, I have a bus pass, I have a bike but I prefer to walk mainly because I like to stay in shape I guess so to speak. What I'd like to do, what I haven't done in a couple years. I haven't done anything athletic. For recreation, I used to weight train. I also did marshal arts as well. Woo Shoo, I guess, is a form of marshal arts I studied for a year. I got into that just to occupy my free time. That's what I like to do. As a teenager growing up I used to draw. I was phenomenal drawing as artistic goes.

I asked this adult if he wanted to draw again:

I know I can draw but I know there's no career. Artists in Canada struggle making a living at art. You really have to put a lot of time and effort in it before you get it back. I have a daughter right? Am I really going to spend my free time drawing and not get any return out of it when I could spend time with my daughter? Last night I took her to her grandpa. I put her in her stroller and we

walked there. That's time spent with my family as opposed to time spent drawing. I have to buy pampers.

This adult is also a fantastic pool player so the CUMFI Wellness Centre had made arrangements for him to give pool lessons on contract through the City of Saskatoon.

Art and music were mentioned as leisure activities by a few of the adults:

I go for walks, I play guitar, write poetry, go swimming. Stuff like... go to movies. I started writing when I was pretty young. It just became something to do, developed as a habit.

This adult has shared some of his poetry and drawings to this study (See Appendix I).

His artistic and poetic talent is remarkable. His drawings are filled with many details and symbolism. It is obvious that his artwork and writing is extremely valuable to him and helps him to process and cope with the realities of his life. He was eager to share his work with me and proud to see that it was valued.

The storyboard shows his personal struggle between the forces of good and evil. He depicts an angel and a demonic figure in the scene, as well as heaven and hell. The destructive forces are powerful and the war is intense. It is very clear that he strives to have faith, and looks towards heaven for salvation and eternal peace with his lady friend.

In his storyboard and his writing, he refers to his blood dad as a scary and oppressive force, and his blood dad ends up in hell. It seems that he associates the masculine as in his unknown biological father with darkness and oppression and the feminine with light and nurturing forces. It is important to note that this adult was adopted at nine months old, and has never met his birth parents. His distress and feelings of loss and displacement still haunt him, as are apparent his artwork and writing. He

refers to his family being reunited and shows his Mom in the picture. He longs to know his biological mother and father.

This adult suffers from schizophrenia and he shared a piece of writing of the different voices he hears. These voices fall into two main categories: the scary, destructive, dark ones and the encouraging, angelic, loving ones. His writing depicts extreme violence and pain, wanting to hurt others and hurting himself. He referenced drug use, violence, crime, rape, gang activities, as reflecting his troubled past. Despite the overwhelming darkness, the drive to be good and his repentance to God is striking and inspiring. I was humbled and deeply touched by this young man's resiliency and hope despite the traumatic obstacles in his life.

Another adult shares her leisure activities:

I do crafts, playing pool I guess here. Swimming whenever I can. Going to the library. Going for walks. I do a lot of different stuff. (At the library) I read, looking for music and stuff like that. (She listens to) country, rock and roll, easy listening sometimes I guess. I do oil painting, cross-stitching, classic canvas, crocheting and trying to learn a little bit about how to knit. Trying to but sometimes it can get pretty tough. Actually my mom was the one who got me into doing them. She used to do cross-stitch, oil painting, needle point and all that.

She does most of these activities on her own but at times she participates in leisure activities at the CUMFI Wellness Centre. She has gone camping with the staff and adults and the Wellness Centre but did not know if she could go this year due to work.

Another adult enjoys coming to the CUMFI Wellness Centre for beading classes that her Mom teaches:

She is teaching us how to bead lanyards and bracelets. Little tiny moccasins we've made, little decorations. She teaches us how to make different stuff. Lighter cases too. Little designs and everything. It's time consuming.

This adult's leisure activities are now restricted as she is a new mom:

Mostly it is like the beading class and sometimes I like going for walks with the baby. That is pretty much it. I used to do pretty much everything. Swimming, go to the zoo – did a lot of things because I actually could. Now I am actually limited.

She did mention some leisure activities she has been involved in at the CUMFI Wellness Centre besides the beading classes:

Camping. And they would take us to powwow. We'd go there with them and have fun. Different powwows, not just... I love powwows. Ya, because it's like a cultural thing. Or they'd have hot dog, steak outs and stuff like that, barbeques. They'd invite us and we'd go and eat. Just to play pool, play the Wii games. When they have birthdays, they'd invite us for cake and icecream. They have little parties there. Métis party kind of thing. We went to that. There was food and everything, music. That was fun.

Staff Perspectives

The CUMFI Wellness Centre tries to work on getting people involved in recreational activities to promote healthy lifestyles and a healthy community. Staff members organize and promote a wide variety of leisure activities.

We encourage them to do exercise, walking. Here we have a Wii game which they play guitar and drums. Also there's bowling, we take adults bowling. We have a pool table upstairs and foosball. They've gone to the golf dome. In the community, we'll go to powwows. Some like to go to round dances and they have gone to the Corn Maze. They do beadwork here as well. It all depends. We have some materials for painting and art. One of the mentors is bringing in some more beadwork as well. We go on outings. We go to the Forestry Farm. We've gone to see the lights at Christmas time at the Forestry Farm and we have barbeques. Basically it is all stuff that they do as a group. A lot of times it is

learning to get along with each other. We also take them out for coffee, just a mentor/adult relationship. They really like going to the Forestry Farm or going as a group to Folk Fest or Taste of Saskatchewan or those kind of things and if things are coming up, we advertise it and remind them about it so they can go themselves too like if there are community events at White Buffalo or a school or whatever.

Other activities that adults have participated in with their mentors are tobogganing, wall scaling, playing basketball, watching movies and attending a Métis culture camp.

Leisure activities can be group activities or individual ones. Group activities are encouraged to promote social skills. Mentors also try to personalize leisure activities by encouraging their adult's interests and abilities.

Through the CUMFI Wellness Centre, they have all the adults come in with their families on Halloween and they celebrate, they have a party. And of course we have the resource room. Since we got the pool table and with the resource room it's just a good atmosphere, so friendly that everyone always has such a good time. Everyone always has a smile on their face. They have board games that they play. They have rock band and what adults want. Last week I took an adult, she said, "I want to do arts and crafts. I need some canvas." We went and bought her arts and crafts and stuff. You always try and find out what they are interested in and help them maintain that and keep that healthy lifestyle. One may like reading so you end up taking them to the library and they take books out or rent DVDs. One wants to go walk by the river so it is always different activities. Back to Batoche is coming up, so they have cultural events going on there when there's stuff happening. Just alone time with the mentors themselves or else mothers that come, that have babies, the mentors will carry the baby and visit and give the mother a break too so they have a lot of positive things going on. There are so many resources out there that they don't know about so as a mentor we try and make them aware, look at all the things? You can be doing that you are good at, or that you would like to be good at. So we let them know that. Like really, you can do this. You can do whatever you want as long as you put your heart into it.

Adults are kept informed about cultural events that are happening such as powwows, Métis days or events at the Friendship Centre. Staff at the CUMFI Wellness Centre encourage their adult's interests:

Right now, one woman, she's always wanted to take piano lessons. She went and found out about a music program through Mothers Music or Yamaha Music or something like that and she'll do ten weeks of lessons and they give her the books. It is my understanding that they lend her a keyboard as well. It costs her one hundred and sixty dollars so we're cost sharing that. She's going to pay one hundred and we'll pay for sixty.

Another adult was encouraged in an artistic way:

I have this one adult. I didn't know that she beaded. She loves to bead. We got her a whole set of and she made her own curtains. She's made earrings and necklaces. She has really got a lot of talent. Even if they have music talent, you try to encourage them as much as you can.

The CUMFI Wellness Centre has a creative solutions fund that can be used on a discretionary basis. Mentors find this fund helpful in providing support and unique solutions to improving the lives of the adults with FASD.

Mentors have found it a challenge to get their adults to attend leisure programming on an on-going basis.

We've tried really hard to get people involved, you know. When the community leisure guide comes out to get people involved in those things but that hasn't been successful. I don't know what it is. Maybe if we get two people to go at a time. I think it is a bit of fear factor. I think it is a couple of things. One it's remembering about it, for sure, and then having the motivation to go out by yourself. If we really concentrated on making sure that people got there but it is kind of hard to do that when we have a heavy day schedule too. I guess the other thing too, if it is evening stuff, I'm careful about encouraging people to do that, if they are going to be walking around by themselves because there is a danger factor.

Many of the adults like to hang out in the resource room to socialize and play pool and the Wii. Staff at the Wellness centre were pleased that they had provided such a positive place for adults with FASD but still felt they need to work on developing their adult's independence towards integrating them into the community. Despite the barriers, mentors believe that leisure activities are valuable to improving the quality of life for adults with FASD.

You know, recreation is so important and it's easy to not make it your top priority if a person is having trouble with a place to live and having food and facing crisis. It's pretty hard to make recreation a top priority. There are other needs. However, I really think that it is important. I think that life satisfaction is a really basic need too.

This mentor summed up what he feels is the social isolation of individuals with FASD and the need they have for support:

I think sometimes people with FASD become very isolated because they have this disability that they don't understand and they don't have friends. Their social circuits are very, very small. We end up becoming almost their friend in that case, their social companion whether it's basketball in summer or going camping or going swimming. We try to have group events a couple of times a month where people we support can interact with others we support.

Finding positive role models to do things with was another need that was mentioned. It seems that some of the adults with FASD do not have helpful friends or family members to do things with. Individuals with FASD can be vulnerable to befriending people who do not have their best interests in mind.

Also I think people with FASD become manipulated very easily too so they fall in with the wrong friend. They end up doing criminal activity and I mean, is that really their friend when they bring them along to steal a car? We talk about positive friends and positive social interactions with people and try to role model those things too.

Summary of Leisure Activities

The adults enjoyed the wide range of activities offered but particularly seemed to appreciate the social aspect of the CUMFI Wellness Centre. They all talked about liking to visit the staff and hang out with friends at the pool table or just chatting with others. This seemed to be valuable to them and as one adult said, going camping with the group, gave him a social unit that he never always had. He had often felt alone in life and appreciated the sense of belonging.

Staff mentioned their concern that the adults were too connected to the CUMFI Wellness Centre for their social needs and wished for them to launch into society more. Although mentorship is provided to encourage adult's independence, the reality is that due to their disability they may also be dependent on the program to some degree. The mentors also struggled with providing leisure activities when the basics of housing, health and safety were often more serious and compelling issues although they saw the need for a better quality of life that leisure can offer.

An individual approach is much appreciated to the adults such as help with keyboarding lessons, purchasing art supplies or setting up the opportunity to instruct pool lessons. Many of the adults with FASD in this study showed interest and talent in the arts. From writing poetry and lyrics, to drawing, cross-stitch, painting, beading and music lessons, the adults showed a passion and skill in these areas. In addition, many of the adults enjoyed sports and physical pastimes as well. An awareness of what adults need is essential as a mentor. There are times adults will choose solitary activities and other times they will wish to be part of group things.

Relationships

Adults Perspectives

Some adults have people they can count on but most of the adults struggled with feelings of loneliness and broken relationships with family members or partners. One adult said that there was no one she could count on anymore in her life. She was upset about relationship issues:

I don't know why she did that. She is always picking on me.

When asked if this was a friend, the adult was adamant that it wasn't a friend:

They are just druggies that pick on me. They think they're better than me but they're not. They just pick on me because they know that I'm doing good and stuff and they just want to bring me down. It's because of the frickin' drugs - that's all. When they don't get something they pick on me and when I get money they start the whole same shit again.

This adult was very upset with relationship issues. She had said about her boyfriend:

"I'm not even sure he's my boyfriend anymore." She was battling to get her son, had problems with roommates and people who were "not even my friend, only when there's money in the situation and they are so called hypothetically 'nice'." This adult does talk to her mentor about these relationships conflicts and she does find this "kind of" helpful.

According to another adult, she has no one she can really count on in her life besides her common-law partner:

To be honest with you, right now – not really because none of my family I would depend on. The only one I actually would is my common-law, I guess common-law husband I would. He would probably be the only one I would. For me it's not that I wouldn't trust him, I would trust him. One thing we both have to work on is we both need to work on trust. It's a big thing for us right now. A lot of

times if I come here, he figures that I am going to do something else and that. That's with him - that is one thing that we are having trouble with right now.

Another adult is not sure about the friends that he has, whether they are a support to him or not:

Ya, I have friends upstairs. A couple of my friends... but they are all too careless. They just talk about it [making positive changes] and they don't do anything about it. Like they talk about their future and then all of a sudden – kind of change [their mind on taking action].

Another adult depends on her Mom for support:

When I am like really mad she listens to me. Lets me get my anger out and then she'll like tease me. Now how do you feel? [she asks] and you can't help but laugh. She's good like that. She knows me. She knows how to make me laugh. Most of the time she listens and that helps because I talk a lot. I have a “muggy” tune – that's like big mouth in Cree. I talk a lot.

This adult is upset by some of her family members:

I don't like my family on the reserve. They are all crazy – I don't know why. They drink a lot and they make us all look bad. Like all of your family drinks, you probably drink too. All of their kids are in foster care and my baby's not. If she did, I would go crazy.

Many of the adults have a history of past abuse from family members or others. Trust can be a big issue for them. They carry these issues into new relationships.

Three of the adults talked about the distress they felt for having children that are not living with them. One of the adults expressed her frustration at her previous partner:

What is his problem? I think is that he thinks I should stay with him because of the kids. But I told him, if I can't see my twins, why would I stay with you? Well one, he was really abusive. He was always hitting me and punching me and every other thing. And even when I was pregnant with the twins, he would kick me in the stomach and everything.

Her twins are three years old and they are with her ex's parents. She talks about losing her rights to them:

It's that the child protection wouldn't listen. I tried to tell them. They kept telling me that the reason that they took my kids was because of the past history of me with my parents. What does that have to do with my kids? I'm not even nothing like my parents. Like one, I don't drink or nothing. Cause my dad, when we were kids, he used to drink a lot. Because I know lots of people who have their kids who are way abusive to them than I was, that they say I was. Then there's stuff in reports, I know that's a bunch of garbage, saying that I supposedly was supposed to throw my daughter out of a window. But when we were young, my brothers were... what I remember when we were kids, the only one that ever tried to throw me out of window was my dad. That was when he was drinking a lot.

Another adult is distressed because she wants to get her son back.

That's why I had to come to court for my son. They want to put him up for adoption but I say "no". I'm going to ask for a pre-trial, do this on my own I guess because he's (baby's father) never helpful anyway. I'm the one doing all the calls for the lawyers, the doctors. All he (her son's father) does is drink free coffee at school and just sit there and get sick so I keep trying to send him home. But the last time I did that he got really sick so I called the ambulance because he wasn't eating. He wasn't taking medications.

Adults often struggle with coming to terms with their disability and feelings towards their mother. One of the adults talks about the feelings he has towards his birth mother regarding his disability:

I talk to my Mom from time to time. My biological Mom swears up and down she didn't do anything but my tests say otherwise, my disability says. In a way, I am kind of angry that I am stuck with a disability. It frustrates me. There's some things that happened before I was born. There is a lot of things. I don't hold a grudge against her but I would like her to say she knew, she knows. Mothers know when they are drinking when they are pregnant. That part I would like. But if she doesn't, I understand. She has gone through a lot. I'm not mad at her. I forgave her a long time ago.

Later the adult again expressed his disappointment that his Mom has not admitted that she drank while pregnant with him:

It sucks. It frustrates me the most. My Mom won't say, "Yes I did [my name]. I'm sorry." Maybe it's a pride issue, she doesn't want to admit but my life hasn't been easy.

Four of the adults interviewed, mentioned their adoptive parents. One adult had Christmas dinner with her foster parents but did not stay long. When asked if they are a support for her she said "I don't know. I got blamed for a bunch of shit at the house too. I don't want to talk about that either." Another adult said "My parents (adoptive parents) are in Vancouver so they can't really help me if I'm in trouble." He did say that he feels support from his sister:

Well, if I ever need to talk she's there. If I need a place for the night she might let me bunk in. She is just there for me.

Another adult said that he was adopted and grew up on a farm: "I grew up in a secure life." He says this about his adopted mother: "She did a good job raising me....She talked to me intensely."

Staff Perspectives

Mentors take on a counseling role when their adults talk to them about relationship issues. Mentors are conscious of promoting independence by not giving their adults answers but helping them come to their own decisions on what is right for them.

They do have a lot of relationship problems. A lot of it stems from either addictions or lack of communication. And some have relationships, like we have, kind of like families as well and they have spousal relationships as well. One of the things is a lack of communication, trust, lack of trust. We listen to what their problems are and one of the things about counseling is listening. The biggest thing is being a good listener and letting them come up with a way as how they

will fix their situation. It is not a lecturing thing. It is like – What do you want to do? It is not what I want to do, it is “What do you want to do?” And it is just talking and listening that they find their own way of solving their situation, relationship problem.

Another mentor added:

Yeah, a lot of my adults – everyone that’s in a relationship, they go through problems once in awhile, so, just being there, being the ear for them. You know, they might not have anyone else to tell, so just be able to talk about it. A lot of my adults, they don’t have a lot of good family support. A lot of the times it’s like, I’m the only positive person in their life. It’s hard to tell them to stop drinking, to stop doing drugs, you’ve got to separate yourself from the people that are doing that, and those people are their family and friends, so, I just try and reinforce. I’m always here, we’re here, the resource room, when I’m not around, is open. You can always come here, make us your second family and just spend as much time as you can with us.

Mentors most often have a close relationship with their adults and have earned their adult’s trust. They become a mentor in personal as well as practical matters.

They tell you everything you know. If they are having a problem, it could be Saturday afternoon, Sunday evening, feeling frustrated and knowing that they can depend on you. They will phone you and tell you what’s going on. They’ll tell you what happened and where it’s happening and how they feel and what should I do? You don’t really tell them what to do. You maybe give them advice or share a similar story and say, “What would you do?” “How would you feel?”

I was impressed by how compassionate mentors were and how they were willing to support the adults with FASD that they worked with after their work hours if needed. It is demanding to work with this population. As a teacher of students with FASD, I am aware of how much emotional energy it takes to support them and deal with all the daily crisis’ that always occur.

And so and so and I are arguing so it is almost like you have to go over there with the other mentor. Is everything ok? Is it that bad? Another one is crying because her and her sister were fighting like simple stuff like that. But you know what? It all worked out in the end because you talk to them and you listen to them and then they eventually... They just need to talk to somebody, somebody to talk to. And that is what's really good about the CUMFI Wellness Centre is that the adults can talk to other mentors so if I wasn't there and somebody else was here, they are comfortable with that because this is such a great environment. We all work as a team. When they do have struggles and stuff we don't leave them hanging at the end of the day at five o'clock. We make sure that they're feeling okay, they're feeling good enough. Just because you are done at the end of the day, doesn't mean it's five – see ya. We don't work like that. You have to, especially with a person who has a cognitive disability, has FASD because they go through so much and you feel for them because you work with them so you know what they're going through. Let's go for coffee and you get them back in the mood again and they're okay again. It's just the support, the smiles, the positive attitude...

The adults with FASD at the CUMFI Wellness Centre seem to be a very trusting group of individuals. They share openly with their mentors and also disclose a lot of personal information to the other adults.

They do share stories with you and they are too sociable with the adults here. Sometimes they will share amongst each other and it is too personal you know. It's just who they are.

This openness is one of their strengths but it can also lead to relationship conflicts when people start to gossip about each other.

Gossiping is a big issue - this person did this and this person did that. We listen to both sides of the story, not being judgmental with any of them - being patient and understanding.

Some of the relationship issues that were shared were about money:

It might stem from a person owing another person, it even stems from money. Just small little things that you wouldn't think would affect them. You have to really find out the whole story. Borrowing money and not returning, even two dollars. Like a money issue.

A staff member relates an adult being upset with a roommate who spent all their money:

“(So and so) spent all the money and now we have no money.” How can you [the mentor] get this person to survive until we get more money again?

Other issues were about family relationships:

I mean it has been quite intense sometimes, like a daughter who really had a poor relationship with her parents but was still living at home and stuff. They would come and do some of their communicating in front of us. It is not like we were mediating or anything but it was just that, I think they were a little more respectful to each other when we were there and so there's been that. And I mean we always encourage people if they are having problems to get those services. So you know – like couples counseling or family counseling or whatever. Of course, like anyone, relationship stress occurred in couple relationships. Then we've got a couple or two, especially one couple, they can't live with each other. They can't live without each other. So I guess we just always talk about the things of good relationships, respectful communication. And we think about empathy because I think that is particularly difficult for people with FASD, is putting yourself in somebody else's shoes and recognizing how others will feel about things so we try to model, role model good relationships.

Summary of Relationship Issues

Many of the adults have experienced relationship failures as in abuse, violence, being put into foster care, poverty and now grapple with anger, low self-esteem and lack of trust in some cases. They seem to value having a mentor to talk to. They mention that they feel better after having someone to express their frustrations with and get some guidance.

It seems important to mention that all of the six adults in this study were adopted or fostered. Some of these adults still struggle with feelings of loss, misplacement, and longing to know their parents. In addition, the psychological damage of moving from foster home to foster home - not having a constant caregiver can not be overlooked. Mentors and the adults themselves made mention to some of their hurt and anger that the adults face in regards to the disruption of their family unit. Some of the adults still wrestle with these issues and are trying to make sense of their lives.

Two of the adults with FASD mentioned their feelings towards their birth mothers. One of the adults talked about the desire to know his birth mother. Another adult tried to process his feelings towards his birth mother. He wished that she would admit that she drank and say that she is sorry because his life hasn't been easy. Counselors and mentors must be sensitive to the psychological impact of adults with FASD who may feel abandoned by their birth parents if they were adopted or fostered.

The mentors are conscientious about not providing direct answers but rather listening and guiding the adult to problem solve on their own. The mentors become counselors in many ways. The mentor is like a 'big brother' or 'big sister' to the adult with FASD, becoming a role model for them.

This area of relationship help was seen as critical by both sides. For the adults, coping with relationship issues was especially overwhelming at times. They face incredible stress and grief from their relationship issues such as being disconnected from their children or their birth parents. Mentors should be open-minded, loving and accepting because of the adult's disability and in many cases their traumatic life experiences.

Self-Esteem

Adult Perspectives

This adult feels quite positive about herself except that she would like to lose a few pounds:

I love myself. I like shopping for myself. Ya, I feel good about myself. [Except] maybe the weight thing.

Another adult's self-esteem fluctuates according to how others treat her:

For me, it's kind of hard to explain it, but for me sometimes I feel good about my life but sometimes when people are putting me down, that's when I don't care about it. I don't care about my self-esteem..... Usually if I am upset or something and I try to talk to somebody and they don't listen and they ignore me. That is one thing that frustrates me. I am frustrated with that. Especially if I am trying to work on something we learned with (mentor), one-on-one counseling, couples' counseling. We learned to try to talk to each other about problems if we have them. But if one person is not willing to do it or listen to it, it is pretty hard for the other person to. For me, that's been a pretty hard struggle for me.

This adult reported "depressed" when I asked her how she felt about herself. She was able to describe her strengths, however. She talked about her ability to play the piano, flute and handbells. She has her own keyboard and likes to play Disney music. She was not able to define her struggles and said that there was "a lot of stuff".

Another adult is frustrated with the limitations in his life right now while he is waiting for his girlfriend to have a baby. This will be his second child and he is eighteen years old. His first child lives with her mother and he doesn't get to see her often:

Everything is going too slow. Have no IDs [identification] and we are still waiting for this young one to come out...Nothing much to do but just walk around and go visit family. Sit here and look after her [his girlfriend]. Feed her, that's pretty much it.

He has some conflicts with his friends. They want him to do things that he shouldn't do and he is struggling to resist the negative peer pressure:

Buy them alcohol and try to get them a phone. They're doing other things that aren't really good. I told them I have no ID.

One adult explains that he was socializing and doing things but he did not feel connected to others on a deeper level and that the CUMFI Wellness Centre has helped him to feel part of a family:

Before I came here, I was very detached. I felt that I was different but I didn't know why. I was going to school at Nutana at the time two and a half years before I knew about CUMFI's existence. I was finding – I was out there trying, you see what I mean. I was working out, I was doing Marshal Arts but I didn't have any friends, any girlfriend. I wasn't dating because I felt that I was distant but I didn't know why. As far as friends are concerned, I didn't have any friends either. Friends I could sit down and talk with. I didn't have the greatest self-esteem. On the outside, it looked like I was this guy who had friends. Really, I just knew people, they weren't really my friends. "Have a good day, bye." After I joined CUMFI [Wellness Centre] I knew I wasn't alone. I knew that there were other people out there with my disability. It became a lot easier to approach people and say, "Hey, how's it going?" once I decided they were going to be friends. I don't like to tell people I have a disability because on the outside you can't see it.

Some of the adults talked about the negative feelings they experienced when they learned of their FASD. One of the adults said "When I first heard about it I did want to die." Another adult stated,

In a way I am kind of angry that I am stuck with a disability. It frustrates me knowing that there are some challenges in my life. I will really have to work hard at some things that some people find easy to do, copy mechanisms.

At the CUMFI Wellness Centre, mentors try to educate the adults with FASD about their disability and one adult talked about how this helped his self-esteem.

My self-esteem has really gone up once I became more educated about my disability. My disability, knowing about it is helpful. It answers a lot of questions about growing up. I wish it wasn't there. I wish I didn't have this disability. ... In a way I am kind of angry that I am stuck with a disability, it frustrates me knowing that there are some challenges in my life. I will really have to work hard at some things that some people find easy to do. Coping mechanisms. Get anxious, have anxiety a little more than another person. I just find I am not picking up on some things quicker than another person. Takes time to think about it harder and try to focus more. Sometimes it is frustrating but it also helps me to know that it's normal, this disability. I've really started to feel comfortable under my skin with it. It's not just me, there's a reason why.

This adult was first diagnosed with Attention Deficit Disorder. As a young adolescent he was diagnosed with Fetal Alcohol Effect:

FAE- Fetal Alcohol Effect. I got that diagnosis when I was a young adolescent, twelve or thirteen. They didn't tell me anything. It was a court order at the time. There was suspicion that something... my lawyer said let's go get you tested. Basically they shaved some time off my sentence because I had that disability. They didn't really explain. No one really educated me about it....They did measurements on me and stuff. They said something about the bridge here. They did something about my eyes. All these little tiny measurements and then they tested my brain and they found out I was FASD but without the effect of the physical features. Mild.

Although, the staff at CUMFI Wellness Centre consider him to be high functioning, he explains the problems his disability causes him:

People get mad at me. What's wrong with you [adult's name]? Why don't you get a job? Why don't you do that? I'm like, "I don't know." [They say] "You know, you know what's wrong." And I get frustrated because some people expect more of me. But really I try. I mean. "Oh, that's just an excuse." [They say] I'm not. "I'll show you the diagnosis." My father-in-law got mad at me. He gets mad at me. I feel pressure from my father-in-law. He gets frustrated with me. He says there is nothing wrong with you. He doesn't understand. He is from the older generation. He wasn't educated about this when he was my age. He just

thinks I am making excuses. I've tried. I've worked before. I get frustrated with people when they say, "There is nothing wrong with you [adult's name]. It's just a piece of paper saying what you are, you are just letting them label you."

Knowing about their FASD can influence how the adults feel about themselves. In some cases, knowing helps the adults to understand their difficulties and this can help them to feel better about themselves. In other cases, they are saddened by the knowledge and awareness of their disability. One adult expresses the grief he felt when he learned that he had FASD:

Well when I first heard about it, I did want to die `cause my adopted mom wouldn't tell me my blood mom's real name and her last name or my blood dad's first or last name. And I wanted to find that out and that made me depressed. But I am adapted to it. FAS doesn't bother me right now but I still want to learn more about it.

Feelings of displacement, being separated from birth parents can be a cause of hurt and low self-esteem for adults with FASD.

This adult distinguished between how he is feeling now versus when he was using substances:

I feel good about myself. I feel a lot more level headed now that I'm not using. I feel more clear. I feel like I am doing good.

When he was using substances he felt 'pretty crappy.'

I didn't like how I felt when I was drinking. Now I look at other people when they are drunk and I think that's what I used to look like and I don't want to be like that.

Some of the adults were able to describe their strengths and others were not. These adults listed their strengths:

I'm friendly with people. I am good at playing music. I am good at writing.

Another adult said:

One, I am good at cleaning, I guess. Communicating I guess. Punctuality. Art, I guess that would be one. Working, like being with others or working with others.

Another adult felt she was strong in caring for others:

Listening. Someone to talk to. I kind of help out with some of my friends with money. Here and there. If they need five dollars, I'm like "ok – here." I like supporting my friends and my family like if they need clothes or something or advice. Of course I'm going to be right in there if they ask me something. Big conversation, it won't end for an hour.

Many adults were also able to identify areas that they struggle with:

Getting up in the morning. Keeping a job.

He thinks that getting up has a lot to do with his medication. Not getting up causes him problems: "If I don't get up, I can't go to work."

Another adult says that her biggest struggles are with her health and her finances.

She can't work now as she is taking care of her newborn:

Like I can't eat healthy. It's like I'm depressed or something. I'm eating a lot lately. Mom says it's cause you're feeding her [her baby] more so you're eating more....All month I never bought nothing. I went to the Food Bank and I asked CUMFI for food and they helped me with that. I have to pay bills. I need the phone.

Living on welfare is taxing and not having enough money to cover things can definitely affect how an adult's self-esteem.

Another adult has difficulty with managing her anger:

Probably from when I was a kid 'cause my Dad always was getting angry with us. I think that could be a lot of it. A person with FASD, they sometimes get mad and not even know why. I know that.

Understanding another's point of view was brought up by two of the adults with FASD as something that is difficult for them. The adult mentioned other struggles as:

I guess trying to work together like with me and (my common-law partner), trying to work things out together. I guess trying to understand where he's coming from and then trying to...

She says the CUMFI Wellness Centre helps her self-esteem:

Sometimes, actually for me, I come here if I need time away from home, when (my common-law partner) is home. It actually helps me to think and get away from the problem. That's how I look at it.

Coming to the Wellness Centre gives her an outlet, a break and an opportunity to talk about her frustrations with a mentor.

Staff Perspectives

According to the research a lot of individuals with FASD suffer from low self-esteem and when I interviewed the mentors, this problem was verified. At times, it seems like adults with FASD suffer from having other people treat them as less capable or less deserving of respect. As one mentor said about how his adults have been treated:

They have to deal with their issues from before and to bring them out so you will have a better understanding of what they are going through. I think from growing up, a lot of people didn't realize about FASD from the past. They get traumatized during the years growing up, relating to the issues they dealt with stemming from the past. Anything, something can trigger their future, can retrigger from the past. They always seem to remember a certain situation so we try to go back and deal with these issues. Like they might have anger involvement from the past. A person being mistreated, or even abused in a certain way, having difficulty to move on. So their self-esteem is pretty low.

Individuals with FASD can also develop a low self-esteem at their places of work:

For instance, I think it is the stereotyping. Say, if you are at work, it starts a lot earlier than that. You have a problem, you never seem to do anything right so people notice that more than they will somebody that is coming along, learning, progressing. All they see is what you can't do, not what you can do.

Mentors saw a connection between their adults low self-esteem with the abuse their adults have suffered.

Well there's often really negative things in their background such as various types of abuse and lots of being victimized. They have probably been the victimizers sometimes themselves too. I think sometimes people are driven to doing things or living in a way that they are not comfortable with. That gives them a negative feeling about themselves and I think it is almost by necessity that they have taken part in some of that stuff. It's not uncommon for people to say, "I've done some awful things in my life." I think it affects the way they see themselves. And of course that is their self-esteem too.

Schools were also mentioned as being a culprit when it comes to low self-esteem of individuals with FASD:

And I do feel that schools just don't... There's just so much of trying to squeeze people or kids into a mold. This is the way you need to be. No matter what your abilities, your tendencies or what your gifts are.

One of the staff members at the CUMFI Wellness Centre felt that earlier support would have helped the adults with FASD to feel better about themselves:

Kind of discouraging for me, anyway because by the time we see people here, being that they are adults, self-esteem is much lower than it might have been if there had been some understanding and intervention at an earlier age.

Mentors see value in encouraging their adults and helping them to achieve their goals. It did get raised by two staff members, however, that adults need to have realistic goals.

Sometimes it's a balance. People can sometimes have too grand a view of what they can do or what ideally they'd like to do. Although I really haven't seen... It's more often talking about it rather than trying to accomplish it.

The mentors stressed the importance of pointing out the positives in their adults, complimenting them and building them up:

Therefore I think bringing their self-esteem up is helping them learn to have goals, a lot of small goals in order to reach the major goal. And complimenting them. You compliment them, opposed to saying, “Well, aren’t you done this yet?” or whatever, in a negative way. You compliment them when they do something good. An inch will give you a mile with them. And I think that is very important for their self-esteem. They know that they can do this. It gives them encouragement. It gives them confidence and I think that is very crucial for self-esteem.

The mentors often tell their adults that they look nice. This can lead to the adults with FASD taking more pride in their appearance and feeling better about themselves.

We always say, “You are looking great today.” We take them out to get haircuts just to boost their self-esteem and buy nice things, something that will make them feel and look better and it does really work. Being clean, their hygiene is a lot better than before. It is good to give them positive words each and every day when you see them.

Reinforcing the positive is a powerful way to help adults with FASD feel better about themselves.

You can tell a lot of the adults – they struggle with self-esteem, make everybody angry, all self-conscious in some way or another. Just when they come in, say, “Did you do something with your hair today?” You know, just reinforcing the positive. I know with one adult, she was always negative, and just saying “Good morning” every day and “you look nice.” Then all of a sudden, she’s saying it every day, and I’m walking in grumpy and everything and she says “Good morning. You look nice today.” I’m like, “Oh!” It just sets my mood for the day. You do it so much that they start teaching you after a while.

It is remarkable to see how adults model themselves after their mentors and begin to be positive role models themselves.

Another issue that mentors thought led to adult's low self-esteem was not growing up in a supportive or encouraging environment at home, especially when drugs and alcohol were involved:

Then a lot of them don't have that positive reinforcement in their household which says my self-esteem is saying, "Good morning. You look good today." They don't get that at home, so when they come here, just doing that. Sitting down, having a cup of coffee, listening to what they have to say. A lot of them they may not even be... Just making sure they are heard and they have a voice and their opinion matters. It gives them a lot of self-esteem. A lot of them, they got this whole attitude whereas "everyone is against me" type of thing. Just being able to break through that and gaining their trust and saying, "You could tell me anything in the world. I am not going to judge you. I am going to help you as best I can and not make you feel like that no more."

Being non-judgmental and understanding are important qualities for working with adults with FASD.

Summary of Self-Esteem Issues

Many of the adults made mention of feeling depressed or anxious and feeling frustrating when other people expect more from them than they can deliver. A few of the adults said that learning about their disability from their mentors has helped them to feel better about themselves and that they wish to learn more. They feel that the staff at the CUMFI Wellness Centre has helped them to feel accepted and encouraged in their individual lives.

The staff has made efforts to positively affirm the adults and compliment them to improve their self-esteem and sees this as effective. They are aware of the fact that many of the adults did not have a lot of positive affirmation in their past. The staff also has

noted that encouraging personal care and hygiene can make a huge difference in how the adults feel about themselves.

The CUMFI Wellness Centre provides a positive, accepting and friendly environment where adults can come and enjoy a cup of coffee in a safe, encouraging environment. Staff also commented on how important positive role modeling and providing an uplifting environment was to the adults with FASD. Staff should note that many of the adults appreciated learning about their FASD and would like to learn more.

Daily Living Skills

Adults Perspectives

Individuals with FASD are known to be sociable. One adult with FASD said:

I know lots of people in Saskatoon because of my profession. I've worked in the downtown district for a number of years and I've met a lot of people. All sorts of groups from the river kids to the street people to the people like [names of people], they're the richest people in Saskatoon.

It is strength to be friendly and sociable but it can be a weakness when individuals with FASD get too involved with negative influences.

Who I associated with last year definitely had a huge factor on my addictions. My addiction has gotten where it is.

When asked about his struggles in daily life, an adult talked about his emotions and his coping skills:

With emotions, I don't know if it's part of my disability or not. Sometimes I find it hard to be emotional. I don't know what it is? Sometimes the neurotransmitters in my brain don't connect when it comes to emotion. Sometimes – give you an example, when I am with my girlfriend and we get into an argument, frustrations of having a family, food, groceries, cleaning, laundry. Get into an argument and it doesn't click to me. My emotions sometimes don't understand

what it is that we are arguing about. I get frustrated and leave for two to three days. I just become numb with my emotions and I don't know if it's normal with people with FASD. It hasn't been easy that I have to struggle everyday with my emotions and anxiety and everything like that. That's why I put my walls up. That's why I've learned to talk good.

Five out of the six adults mentioned the help they receive in getting rides to go grocery shopping and to do other errands: "She [mentor] helps me out. She picks me up and takes me grocery shopping." Another adult said the rides were helpful to her because of the cost of taxis:

Just bringing the stuff back because cabs are so frickin' expensive these days. Cabs are pretty expensive.

This adult would like to have help from his mentor in getting his identification back:

Lost my SIN card at a park – my whole wallet never mind. And then I lost another wallet just a couple days ago.

One adult appreciates the help her mentor gives her in clothing shopping:

Sometimes I go clothing shopping (with my mentor), stuff like that for clothes and that. Sometimes for me it is pretty hard to find sizes of clothing.

At the same time this adult is adamant about her desire to do things independently. She does not want too much help. Although she appreciates help at times, she wants to learn to do things on her own as well:

But sometimes too, like I told (the program director), I do like trying to do it myself too to show people that I can do it myself. Do it independently.

An adult shares how the CUMFI Wellness Centre is involved in her daily life:

They help me a lot, mostly with rides. If I need faxing done, they would help me with that. And sometimes I like talking with her (her mentor) like emotionally stuff. Like about her Dad (her baby's Dad), that's emotional.

Two of the adults had not eaten anything yet that day, when I interviewed them in the afternoon. One adult said he just got up and the other adult had no food:

I had to throw everything out in the fridge. I haven't been home for the past four days. No point in going home myself 'cause I'll hurt myself. I just feel depressed. I don't like to be alone, that's the thing but I am always alone.

It seemed the adult had to throw things out because her power had been cut off and the food had spoiled. She had not eaten for a few days.

Some adults expressed an interest in learning cooking skills. There has been cooking classes housed at CUMFI that some of the adults have participated in. One adult talks about her interest in learning to cook better:

There is a lot of stuff I don't know how to cook because being in foster homes where I lived. They always had a house mom there to cook for you so you really didn't get shown how to cook.

She said she would like it if her mentor taught cooking skills. Another adult has asked her mentor how to cook spaghetti:

So I ask her how to cook some stuff and she tells me. Like my spaghetti usually comes out weird. You should cook it for me sometime. (she asks her mentor) "No way, cook it yourself." (her mentor answered) She told me how. I was like, "okay."

Staff Perspectives

One of the supports given to adults with FASD at the CUMFI Wellness Centre is help with their daily living skills. The mentors spend a great deal of time taking their adults to various appointments. As well, many adults are helped with grocery shopping on a regular basis. Occasionally some adults are helped with cleaning their places.

help with appointments.

Taking adults to appointments seems to be a great deal of the support that is provided by mentorship.

The daily living, the appointments, the mentors usually help them with either transportation or setting up initial appointments if they have a problem and they can't set it up themselves. We encourage them to set up their appointments and we will ensure that they get there. But if they can't, they don't know how to get to point a and point b and we try and teach them. You have an appointment when? For the next three months you have to go here, here, here. We also keep a log of it just in case we have to remind them as well as remind ourselves. They don't always remind us - I have to go to this appointment. On a daily basis, some have to go to social services, some have to go to probation, some have to go to court. So all of these, it's a daily exercise for the mentors too. Okay, I have ten adults: I have six doctor's appointments, two court cases, social services, probation on such day so it's a... you also want to have time with them for social.

Not every adult needs help with making and getting to appointments but many of them do.

Appointments – boy that's a really big one because, again some people are really good at making appointments and can be less good at remembering them or having the motivation to go. Especially if it is new, having a mentor to go with is really important. We have to think about how we feel about doing something strange by ourselves especially if it is going to be something difficult like going to Tamara's House (for women who have been sexually abused), going to counseling things that are going to take an emotional toll, seeing a lawyer, going to court, all of those things and those are all really important as you know so people don't get caught up in the justice system forever because they're missing their appointment or breaching their conditions or not getting the certificates or what they're supposed to do so that is a huge one and having the justice worker has been terrific. As far as other things, finding housing, I guess we talked about that, just being able to go along with people often gives them a bit more credibility so they'll be listened to or they'll be looked at more favorably and make sure the communication is there so everybody understands what's going on.

Getting to appointments is important, especially ones for probation or medical attention.

The support can range from scheduling appointments, reminding their adults to go, driving them there and/or being at the appointments to advocate for them. Adults vary on their need for help with appointments as with all the other services offered at the CUMFI Wellness Center. According to one mentor:

Everyone is unique. Some are very good. Others will keep asking, “When is my appointment?” or they will need a reminder especially some it is the day before, a couple of days before. Some it’s like, I’m picking you up in an hour, we have to go! Some are very good at it. Some aren’t as well organized.

grocery shopping, cooking and nutrition.

Taking their adults grocery shopping was a common support given to adults at the CUMFI Wellness Centre.

With grocery shopping – it is a bit of lesson. This is the cheaper way of buying that or this is a more nutritious way or let’s make sure you have the basics before we go to chip isle. So lots of the shopping we do is because it is important to catch people when they first have their money to spend it where they need it rather to be used for drugs or alcohol or computer game or something like that. We do those things and, at the same time, encourage people to do what they’re capable of, there’s that line between helping and overwhelming.

Adults are reminded to take care of their nutritional needs. At times, mentors will prepare food for their adults at the Wellness centre. I was at the Wellness Centre waiting to conduct an interview with an adult when her mentor asked her if she had eaten and prepared her a cup of tea and a chicken pot pie.

I was even making sure that they get their three square meals of the day and CHEPs has even helped them out with having fruits when they come in here at 10 am and you say, “Did you have breakfast?” And they say, “No.” We give them fruit or we will whip up something in the kitchen for them, just to make sure that they are getting their breakfast because it’s the most important meal of the day.

It seemed like cooking classes were well-received by the adults with FASD.

At White Buffalo we take them to cooking class. We actually had a few here - that teaches them importance of nutrition. That really helped them. Whatever they cook, they get to take home. And that's what we implemented in the kitchen downstairs for them too. It brought everyone together. And then they were chatting and enjoying the meal and wanting to share.

setting up schedules and routines.

Individuals with FASD do well with structure and routine.

They like to be organized. Organization. Scheduling, routine.

Mentors at the CUMFI Wellness Centre can play a role in helping their adults establish schedules and routines that will improve their lives.

Some adults of mine, they didn't have time for themselves. Like a time out so I got their kids into daycares then they'd have the afternoon off. They'd go home and then they'd organize their house. Get them the afternoon to do laundry and catch up for things for themselves or just sit down and relax. Just going out for coffee and talking. Making a routine for the... scheduling time, if they just want to talk to someone and go out.

Mentors have helped adults, who were sleeping all day, to get up in the morning.

A lot of my adults when I first started working with them, they would wake up at two pm, get up, smoke for breakfast, drink a Pepsi. Just the nutritional value of it, just making sure. "Get up at eight am," and they would come up with an excuse, "Well, I don't have an alarm clock." So by Christmas we got a whole bunch of alarm clocks and we gave everybody one so nobody had that excuse any more. They argue and say, "Well, what do I have to get up for? And then, I say to them, "Well, you are looking for a job, right? OK, what happens when you get a job, you are going to have to do this anyway. If you are already doing it, it is going to be a whole lot easier to go to work." [It will] be a whole lot more enjoyable for you to go to work if you don't have to alter your schedule that much. You are already getting up. You might as well go to work. You are already going to sleep

at a reasonable hour.” Just giving them things we take for granted, going to sleep at a reasonable hour, getting up, that’s to set their mind.

housekeeping.

Adults are sometimes helped with housekeeping tasks. Mentors have gone in and cleaned up some adult’s residences. Then adults would not feel overwhelmed and they would be better able to maintain their home.

Cleanliness for sure. There are some that have a hard time being a single parent. Some of them are single parents dealing with small children. Caring for small ones, cleaning up after them. Plus they have disabilities, they have a bad knee and it is hard for them to bend. You have to get access, like a dust pan to pick up something. That means so much to them. That really helps them out a lot too with the cleaning and stuff. Even if they needed laundry done. We would take them.

cleanliness and hygiene.

A mentor took one of his high school adults to have a shower every morning and to ensure that he had clean clothes. This young man did not have the best living conditions or good habits of hygiene from his caregivers.

Summary of Daily Living Skill Issues

Adults were positive about the help they received in getting rides for groceries and other appointments. One adult has insight that his FASD might be the cause of his emotional problems. This unstable emotional state can cause adults with FASD to struggle with their daily living skills. They need someone to help them move past their stuck state to form good habits and structure.

The staff talked about the importance of helping many of the adults with their daily schedule, by making the appointments and encouraging them to structure their day. The staff provided help with house cleaning and organization for some adults.

The adults are open to assistance when they need it but they want to develop their independence as well and sometimes would prefer staff to let them do it on their own. Many of the adults mentioned that they would like to learn cooking skills from their mentors or through classes. The CUMFI Wellness Centre has provided some cooking classes but the adults seem to want more instruction in cooking and more individualized help as well.

Court Issues

Adults Perspectives

One of the adults I interviewed was incarcerated. In a research study on individuals with FASD, 60% of them had experienced trouble with the law (Streissguth & Kanter, 1997). This adult talks about why he thinks people with FASD struggle with the law:

They don't know what they did wrong. Most of the people with a disability don't know they did wrong. But after they are punished, they feel real bad about it.

The adult said that he was incarcerated this time for:

Not taking care of my undertaking [probation matters]. My girlfriend forgot to give me my undertaking and basically just my conditions that got me in trouble.

He said that in the past:

When I was younger, the drugs and alcohol had something to do with it.

He also made reference to his schizophrenia as causing him problems with the law:

Well in the past, I listened to my voices when they told me to do bad stuff. Now I don't do bad stuff, I only do the good stuff they tell me to do.

This adult feels reassured that his mentor and the justice worker at the CUMFI Wellness Centre will be present at his court date:

My worker (Justice worker) said she'll probably be present with (my mentor) tomorrow (his court date). Well they (the Justice worker, his mentor) speak on my behalf and explain my story to the court. Just let them know that I am going to be assessed to get help. Stuff like that.

Staff Perspectives

The CUMFI Wellness Centre employs a justice worker. She is able to help the adults with FASD with court matters. The justice worker talks about the need for this service:

The majority of them do end up in the court system somewhere along the line. Especially when children are apprehended from mothers and men that are in their thirties but really have the mentality of... After they are diagnosed with FASD, or bipolar or schizophrenia and they need help and that's where you get a team involved.

The justice worker plays an important role at the CUMFI Wellness Centre. She is able to advocate for adults and help them understand the legal system when they get themselves into trouble with the law.

Summary of Court Issues

This adult felt comforted by knowing that his mentor and the justice worker would be present to help him represent himself in court. This adult felt that sometimes adults with FASD do not understand what they did wrong in terms of breaking the law. Addictions as well as mental health issues can also contribute to trouble with the law.

The justice worker is a valuable resource available to adults who need advocacy in legal matters. There is a greater need for awareness and communication among legal staff on the vulnerability of individuals with FASD having justice issues.

Chapter V: Recommendations and Conclusions

Summary of Findings

My first objective was to better understand the lives of adults with FASD. I was honored by the openness and honesty of the adults. In addition, the commitment of their mentors was impressive. From getting to know the adults with FASD through the CUMFI Wellness Centre I was struck by two things - their struggles and their resiliency. The adults I studied had been through much in their lives and yet they were all striving to better themselves. From trying to learn more about their disability, to taking classes, to efforts to avoid substances, to finding employment or taking piano lessons, the adults showed spirit, resilience and hope for their future.

I was impacted by learning about their struggles such as their difficulty with housing, financial stress, addictions, mental health issues and trouble with the law. Many of the adults also suffered from low-self esteem, depression, feelings of anxiety and relationship loss such as being in foster care or losing care of their children. I was reminded how difficult life is for all of us and how individuals with FASD face even more life stress precipitated by their fetal alcohol impairment.

My second objective was to report on the impact of the CUMFI Wellness Centre on the adults with FASD. The adults valued the opportunity to talk to their mentors to work through life stresses but they also appreciated help with day to day things like grocery shopping and filling out forms. Many of adults come to the CUMFI Wellness centre on a daily or weekly basis and they view the staff as family. Their attachment to their mentors was evident and I noticed the sense of security they felt to know that there was someone available when they needed to talk or needed help in some area.

I was impressed by how favorably the adults viewed the CUMFI Wellness Centre. The comfort of talking to their mentors and the safe, positive social environment seemed to mean a lot to the adults with FASD:

I get here whenever I can, once or twice a week. I guess just being (to get away) from home. I can shoot pool here or play Wii or talk to the mentors. I can't do that at home. Just the people that are here. I like coming here having coffee once in awhile. I just like the people that hang out here.

The program coordinator helped this adult work through things. He applies the guidance he receives at the Wellness Centre to better his life:

I come here and talk to her (program coordinator) whenever I want even if someone is bugging me. I try to do my best about what they tell me. They really give me a lot of good information here so I take that and use my best abilities and try to do something with it.

All of the adults that were interviewed appreciated the support they felt from having someone to talk to.

My final objective was to provide recommendations on how to best support adults with FASD. The ten recommendations that I listed below evolved from the interviews with the adults and the mentors as the most important issues to improve upon. Basically the adults and the mentors believe the mentorship program at the CUMFI Wellness Centre is effective and is serving its purpose. The changes that are needed are mostly from a societal level: more available and supported housing, increased funding, changes to social services and more awareness and understanding of all of society on the issues facing adults with FASD.

In summary, adults with Fetal Alcohol Spectrum Disorder who received mentorship at the CUMFI Wellness Centre valued the support they received from the program. They

felt that it increased their quality of life. The results of this study highlights specific ways that mentors have worked with adults with FASD, what supports are most needed and what additions or changes can be made to help these adults further. As my literature review highlighted, there is already a great deal of evidence about specific lifelong challenges for individuals with prenatal alcohol exposure. What is needed is more focus on the lifelong supports that must be provided. We cannot undo the brain damage and primary disabilities of FASD but by increasing our understanding and our support, we can decrease the occurrence of secondary disabilities. A mentorship program such as the one at the CUMFI Wellness Centre in Saskatoon, Saskatchewan can provide on-going support to adults with FASD to not only improve their lives but also the lives of their families, caregivers and all of society.

Recommendations

1. Adults Need for Help Balanced with their Need for Independence

The adult's desire for autonomy conflicting with their wish for support was a challenge that was impressed upon me. Support staff and caregivers for adults with FASD must be aware of this balance. In this study, the adults vocalized when they appreciated help and when they wanted autonomy. Support staff must respect their wish for autonomy.

Adults with FASD want to make decisions about their lives. They want to be respected. Here is an example of an adult's viewpoint of wanting to have more opportunity to choose the help she receives:

One thing I am going to say, I don't know if [staff member] will get mad at me or not? If someone doesn't want help with something they should, what's the word? Respect. With me and sometimes with my boyfriend, asking him all the time what he's doing, where he is working. It is nobody's business but his. Privacy, also whatever we're doing for jobs and that. It's our concern. Not theirs because we're the ones working for the money. That's how I look at it.

They like to be able to try things on their own yet they still want support. All the adults in the study were appreciative of support: rides to appointments, help with accessing social services, finding housing, support in court, explanations about their disability and someone to talk to.

Adults want respect and the opportunity to get help in areas they wish and yet at the same time it is natural that mentors will try to encourage them in ways they may not want help in. This seems like one of the difficulties of offering a mentoring service – when to offer help and when to let adults to their own devices. It is not an easy line to find.

I understood the challenge for the mentors to know when to offer assistance and when to step back and let adults with FASD make their own choices and possibly mistakes. Mentors are by nature caregivers and their desire to help the adults that they work with may compel them to offer more help than the adults always wish to receive. Yet, it seems critical that anyone working with adults with FASD have a respect for their autonomy and independence. Their humanity and their self-esteem must be honored by respecting their freedom of choice regardless of their decisions.

2. Family Issues Affecting the Adults with FASD

Dealing with issues of being fostered or adopted affects the psychology of many adults with FASD. Their feelings of loss and abandonment can follow them through their life and lead to self-esteem issues and insecurity. Many of the adults expressed mixed

feelings of hurt, anger and a desire to know their birth mother. Three of the adults also expressed feelings of sadness, remorse and frustration that their children were not living with them. Mentors must provide avenues and tools for these adults to work through this psychological pain.

3. Need for more Mentorship Programs

There is a waiting list of adults with FASD to get into the mentorship program at the CUMFI Wellness Centre. There is obviously a need for more of these types of programs. One mentor talks about the need he sees for more mentors:

Even another male and female mentor. We've got a waiting list. It would be nice to not have a waiting list, to offer services right when services are needed. When someone's phoning here and they have nowhere else to go, and they give us their whole big story and we're feeling bad, and then they say, "Can you help?" We say, "Well, there's a waiting list and our services are ongoing. It could last forever."

It is difficult for mentors to turn away adults with FASD who are requesting help because their program is full. It would be ideal to have enough services to meet the needs of adults with FASD.

4. More Appropriate Low Income Housing and Supported Housing

The need for appropriate housing for adults with FASD was also emphasized in this study. The adults related their stresses over finding appropriate housing and their appreciation for help from the mentors. More and better housing needs to be available for low-income families. In addition, supported housing is a necessity for some adults with FASD. The Hessdorfer House that the CUMFI Wellness Centre manages with a "house parent" living on site is a good model. The adults living at the Hessdorfer House valued the feeling of safety and security there.

5. Modifications to Social Services

Social service providers need to be aware of the difficulty of some adults with a cognitive disability in accessing their services. Some adults with FASD will need assistance in filling out forms. They may also need someone to help explain the services available and how to access them.

In addition, the mentors at the CUMFI Wellness Centre expressed the need for social services to change its policies to give people more incentive to work. They suggested that social services keep adults on file as they are attempting to work so that if the work placement doesn't work out, adults don't have to start over again. Mentors reported that the adults were hesitant to work because of this current policy.

6. Awareness and Advocacy in Justice

There is a continued need for understanding and awareness of the vulnerability of individuals with FASD in getting in trouble with the law. The life-long neurological impairments found in people with FASD can increase their susceptibility of victimization and involvement in the criminal justice system (Fast & Conry, 2009). The Justice worker employed at the CUMFI Wellness Centre provides advocacy for adults with FASD in dealing with their probation and court issues. She reported the high demand on her time as she helps the adults at the CUMFI Wellness Centre with their legal issues. Three of the adults in this study, expressed their relief that they could count on the justice worker's knowledge, support and mentorship in justice issues.

7. Mental Health Awareness and Treatment

More research is needed on the link between mental health and FASD. Mental health may be a primary disability of FASD rather than a secondary disability. In a large scale

clinical study, 94% of individuals with FASD reported mental health problems (Streissguth, Barr, Kogan & Bookstein, 1996). It is significant that in this ethnographic study, four of the six adults spoke about mental health issues they were facing. Two adults admitted to feeling depressed during their interview. One of these adults was afraid she was going to hurt herself. Another adult explained the anxiety that he constantly battles. Another is diagnosed with schizophrenia and has spent time in mental health treatment centers during the time of the study. More education and awareness about mental health issues affecting individuals with FASD is needed as well as increased mental health services.

8. Addiction Services Designed for Individuals with FASD

There needs to be more research on effective substance abuse treatment programs for individuals with FASD. Many treatment programs use a cognitive behaviour model which often does not work well for adults with FASD. Cognitive therapy programs pose an issue for individuals with FASD who have difficulty with executive functioning and cannot link cause and effect consistently (O'Malley, 2007).

Staff at treatment programs should be trained on FASD and specifically how to best work with this population. Treatment programs need to be developed specifically for individuals with FASD. Individualized additions treatment or partnering them with a mentor can be a more effective model. A mentor at the CUMFI Wellness Centre, who is also trained as an addictions worker, has been developing a treatment program to use specifically with the adults with FASD that he works with. Support and mentorship programs can also decrease the likelihood of adults with FASD needing substance abuse treatment.

9. Outreach Workers

Staff at the CUMFI Wellness Centre expressed the need for an additional staff person or persons who would be able to go out into the community and find people or meet with previous clients who need help. Adults who are not functioning well because their mental health issues increased or they fell into addictions may stop attending the mentorship program.

Mentors are kept busy with a case load of adults who engage but wish they could also help those who are not coming. I experience this in the education system as well. An outreach worker would help the education system reach young people with FASD who are not getting to school but who desperately need help. One mentor explains how an outreach worker could really help their efforts to reach adults with FASD who need support:

Sometimes when you don't see people it's because they're doing really well and they really don't need anything or sometimes they are in a funk. We really try to do outreach and make those connections but it can be difficult if you're not able to track someone down five times in a row or something like that.

10. Increased FASD Education

Many of the adults with FASD wished to know more about their disability. They related that is helped them to feel better about themselves to understand their disability. A greater effort should be made in teaching individuals about how their fetal alcohol exposure affects them. FASD education needs to be part of professional training in child care, education, law, justice, medicine and social work. In addition, employers need to be educated about FASD in the workplace.

The Saskatchewan FASD Speakers' Bureau is a group of speakers trained to give presentations on FASD. The group is a partnership with the Saskatchewan Prevention Institute and the FASD Support Network of Saskatchewan. I am a member of the FASD Speakers' Bureau and have provided training to high school students, post-secondary students as well as to professionals in the areas of education, social work and justice.

Efforts need to be continued and increased in FASD prevention. It is heartbreaking to see the way that fetal alcohol exposure can affect an individual's life. Substance abuse education and FASD awareness should be a mandatory part of the school curriculum at every grade level.

Conclusions

In summary, the mentorship program at the CUMFI Wellness Centre improves the lives of adults with Fetal Alcohol Spectrum Disorder. As evidenced by the data collected, the mentorship program is valued by the adults with FASD that it serves. All of the adults with FASD spoke favorably about the mentorship they received. One adult stated that if the program was taken away "life would be a lot harder."

The mentorship program at the CUMFI Wellness Centre in Saskatoon, Saskatchewan provides an effective model on mentorship for adults with FASD. Mentorship provides adults with FASD links to community supports, housing, education and employment. Mentors increase the efficiency of the social support system by bridging communication between adults and social support workers. Mentors can coordinate the adult's supports to help ensure that services are not duplicated.

It is my strong recommendation that government increase funding to long-term support for adults with Fetal Alcohol Spectrum Disorder such as the mentorship program at the CUMFI Wellness Centre. By increasing support for adults with FASD, government can be proactive rather than reactive. An estimated \$1.3 million is spent in Canada over an individual with FASD's lifetime (Hopkins et al., 2008). Although the cost of mentorship has not been analyzed, it is obviously more economical to provide support to adults with FASD to reduce negative outcomes.

Mentorship improves the health and quality of life for adults with FASD. Funds earmarked to help adults with FASD become healthy and productive members of society decreases negative outcomes, both financially and ethically, of unemployment, homelessness, family violence, incarceration, addictions and mental health treatment.

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Appendix A: Ethics Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Bor-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
Amy Eason

DEPARTMENT
Education, Psychology and Special Education

BLIS
06-133

INSTITUTION WHERE RESEARCH WILL BE CONDUCTED
University of Saskatchewan
Saskatoon, SK

STUDENT RESEARCHERS
Claire Ann Schwaninger

SPONSOR
UNDEFINABLE

TITLE
Support to Follow the Lives of Adults with FASD: An Ethnographic Study of a Mentorship Program

ORIGINAL REVIEW DATE
03 Jun 2009

APPROVAL ON
25 Jun 2009

APPROVAL OF
EPLES Application
Consent Form, etc.

EXPIRY DATE
27 Jun 2010

Full Board Meeting

Date of the Board Meeting: 25 Jun 2009

Delegated Review

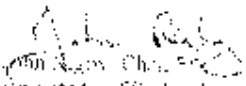
CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-stated research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other certification or regulatory approvals that may pertain to this research project, and for ensuring that the outlined research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there are no changes to experimental conditions or research procedures.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair of Research Ethics Board consideration in advance of implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a main report must be submitted to the REB Chair for Board review. It is the responsibility of the investigator to ensure that each year the study remains open and operational until completion. Please refer to the following website for further instructions: <http://www.ugggh.com/ethics/ethics.html>

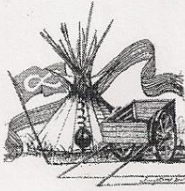

Chair of Research Ethics Board
University of Saskatchewan

Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 2669 RMC, Saskatoon, S0N 0A0, Saskatchewan
Saskatoon, SK S0N 0A0

Appendix B: CUMFI Wellness Centre



CUMFI Wellness Centre
315 Ave M. South
Saskatoon SK S7M 2K5
Phone: (306) 975-0325 Fax: (306) 975-0388

Background Information:

The CUMFI Wellness Centre was established April 1, 2007 through a partnership of the Saskatoon FASD Supported Housing Project and Central Urban Metis Federation Incorporated (CUMFI), and is funded by the Saskatchewan Cognitive Disability Strategy (CDS).

The Service:

The major focus of the CUMFI Wellness Centre is mentoring services for older youth and adults with a cognitive disability. Mentoring is defined as providing support according to the unique needs and goals of each individual. It may include assistance:

- In obtaining and maintaining appropriate housing;
- In accessing required services and resources, including income security and health care;
- In money management and bill paying;
- To building on strengths and interests to become involved in recreation, obtain and maintain appropriate employment, develop pro-social relationships and build self-esteem;
- In decision-making and remembering, as well as the many tasks that are part of daily living. These activities include one-on-one participation and teaching regarding personal care, nutrition & wellness, setting up daily routine charts, shopping, cooking, food safety, child care, housekeeping, making and attending appointments, providing transportation and companionship, etc.

The exact activities undertaken with each person are individualized, according to their unique strengths, needs, and interests.

Criteria for Services:

Diagnosis of a cognitive disability or characteristics consistent with a cognitive disability; no or limited services accessed through Community Resources or CDS

The Staff:

Includes 6 positions:

Project Coordinator: Eunice Bergstrom

Mentor:

Mentor: Terence A. [redacted] (975-03 [redacted])

Community Liaison/Office Coordinator: [redacted] (975-03 [redacted])

Mentor: Nicholas McCormick (95- [redacted])

Mentor: Adeline Switlocke (9 [redacted])

There is flexibility in the scheduling of staff, so that they are available when necessary in the evenings and on weekends.

24 Hour Telephone Backup: Is provided by the staff at Infinity House who are available 24 hours per day.

Resource Room:

A resource room where people are welcome to make use of the printed and video information about cognitive disabilities is part of the CUMFI Wellness Centre. The resource room also provides a place for people being supported and their mentors to spend time. Appropriate activities are developed in the resource room according to the interests of people receiving services.

Appendix C: Adult Consent Form

You are invited to participate in a research project called
Supports to Improve the Lives Adults with FASD: An Ethnographic Study of a Mentorship Program.

Researcher:

Carrie Ann Schemenauer
Special Education Masters
University of Saskatchewan
Contact numbers: 477-2174 hm 229-4101 cell

Purpose: To discover what supports are helpful for adults with FASD and what areas that these individuals could still use help in. The research will be used to help adults with FASD and their families to get better supports for living with FASD.

Procedures:

The research will:

- 1) conduct at least three 30-45 min interviews (tape recorded) with you in a private room in the CUMFI Wellness Centre
- 2) at your invitation, spend time with you and your mentor, and take notes on the mentorship
- 3) welcome any other items you would like to share such as something you wrote
- 4) give you the opportunity to remove anything that you have said
- 5) publish the final report and share the findings
- 6) information will be stored by the research supervisor for at least 5 yrs, after this, the information will be destroyed.

Potential Risks: It is possible that after sharing your thoughts in an interview, you may begin to feel upset or sad thinking about things in your life. If this happens, please let myself or the staff at CUMFI Wellness Centre know so that we can connect you with counseling.

Confidentiality: We will not use your real name in the report. We will try to take out information that may identify you. You can decide if you want to remove something you said from the written report. If you share anything that is illegal or potentially incriminating, you need to know that we our reports may be subpoenaed. However, we will not have your name on anything except the consent form. If you share information that shows intention to harm yourself or others, we must seek the appropriate help and can not keep this information confidential.

Right to Withdraw: It is always your decision to be involved. You do not have to answer a question, if you do not want to. You can also decide at any time that you know longer wish to be interviewed and we can take you out of the study. If this happens, we will destroy any information that you have shared with us.

Questions: If you have any questions about the interviews and observations, please feel free to call me at 477-2174 (Carrie Ann Schemenauer).

This project has been approved by the University of Saskatchewan Behavioral Research Ethics Board on June 23/09. If you have any questions about your rights, you can call the Ethics Office (966-2084).

Part 2: Informed Consent Form

1. I understand that I am agreeing to take part in about three, 30 – 45 minute, one-on-one interviews with the researcher.
 Yes
 No
2. I understand that my interviews will be tape recorded.
 Yes
 No
3. I understand my participation is (voluntary) my choice and I can leave the study at any time. If I leave the study, no one will be disappointed and there will be no change in my services.
 Yes
 No
4. I understand that this research may be subpoenaed by a court of law. The researcher will caution me if I begin to talk about illegal activities.
 Yes
 No
5. I understand that if I talk about something that is harmful to myself or others, this information can not be kept confidential.
 Yes
 No
6. I understand that Carrie Ann Schemenauer (Master of Special Education) and Roy Thurston (Thesis supervisor) will have access to the information I provide.
 Yes
 No
7. As an adult with FASD, or FASD characteristics, I am legally able to represent myself and understand what I am agreeing to about this research study.
 Yes
 No

This study was explained to me by _____

I agree to participate in this study as explained above.

(Signature of Participant)

(Date)

(Signature of Researcher)

Appendix D: Staff Consent Form

You are invited to participate in a research project called **Supports to Improve the Lives Adults with FASD: An Ethnographic Study of a Mentorship Program in Saskatchewan.**

Researcher: Carrie Ann Schemenauer

Special Education Masters

University of Saskatchewan

Contact numbers: 477-2174 hm 229-4101 cell

Purpose: To discover what supports are helpful for adults with FASD and what areas that these individuals could still use help in. The research will be used to help adults with FASD and their families to get better supports for living with FASD.

Procedures:

The research will:

- 1) conduct at least 2-45 min tape recorded interviews with you in a private room in the CUMFI Wellness Centre
- 2) at your invitation, spend time observing the mentorship with you and your adult and take notes
- 3) give you the opportunity to remove anything that you have said from the study
- 4) publish the final report and share the findings

Potential Risks: It is possible that talking about the mentorship you do with adults with FASD may bring up issues that are sensitive to you. Please let me know and I will give you contacts for counselling services.

Confidentiality: We will not use your real name in the report. We will try to take out information that may identify you. You can decide if you want to remove something you said from the written report.

Right to Withdraw: It is always your decision to be involved. You do not have to answer a question, if you do not want to. You can also decide at any time that you know longer wish to be interviewed and we can take you out of the study. If this happens, we will destroy any information that you have shared with us.

Questions: If you have any questions about the interviews and observations, please feel free to call me at 477-2174 (Carrie Ann Schemenauer).

This project has been approved by the University of Saskatchewan Behavioural Research Ethics Board on June 23, 2009. If you have any questions about your rights, you can call the Ethics Office (966-2084).

I agree to participate in this study as explained above.

(Name of Participant) (Date)

(Name of Participant) (Name of Researcher)

Appendix E: Interview Questions for Adults with FASD

How is the CUMFI Wellness Centre involved in your daily life?

What could the program do to better help you?

What areas of your life do you need help in?

Appropriate Housing

Where are you living right now? How do you feel about where you are living?

How has this program been involved in your housing situation?

Employment

Tell me about your job.

Tell me about your efforts to find work.

Describe this programs involvement, if any, in finding and keeping a job.

Money Management

Describe your mentor's involvement, if any, in paying your bills and managing your money.

Accessing Services

Describe this programs involvement, if any, in helping you access services such as health care or income security?

Leisure Activities

What do you do for leisure?

What things would you like to do for leisure?

Describe this programs involvement, if any, in your leisure activities.

Relationships

Do you have people that you can depend on in your life? If so, describe one of these people and how he/she is there for you when you need them.

Do you have any problems with a friend or family member that is upsetting you? Describe.

Describe your mentor's involvement, if any, in your relationships with your friends and family members.

Self-Esteem

How do you feel about yourself?

What are your strengths? What do you do well?

What areas do you struggle in?

Daily Living Skills

Tell me about how you do your grocery shopping?

Describe your mentor's involvement, if any, in your grocery shopping. (Where do you shop?

Do you follow a budget? What foods do you buy?)

Tell me about what you have eaten today. Has your mentor talked to you about nutrition?

Explain.

Tell me about what kinds of foods you cook?

Describe your mentor's involvement, if any, in your ability to cook.

Appendix F: Interview Questions for Staff

How is the CUMFI Wellness Centre involved in the daily lives of adults with FASD?

What could the program do to better to serve adults with FASD?

In what areas do these adults need more support?

Appropriate Housing

How has this program been involved in the housing situation of adults with FASD?

What are the main challenges these adults have with housing?

Employment

Describe this programs involvement in employment of adults with FASD.

What are the main challenges these adults have with employment?

Money Management

Describe your involvement in helping your adults with FASD in the area of money management. What do you see are the main challenges these adults have with money management?

Accessing Services

Describe this programs involvement in helping adults with FASD access services such as health care or income security?

Leisure Activities

What do the adults with FASD do for leisure?

Describe this programs involvement in leisure activities of adults with FASD.

Relationships

Describe your involvement in relationship issues that your adults with FASD have with friends and family members.

Self-Esteem

What do you feel are the factors that influence the self-esteem of your adults with FASD?

Daily Living Skills

Describe your involvement in the daily living skills of your adult with FASD? (ie. Grocery Shopping, appointments, nutrition, exercise, cooking)

Appendix G: Data/Transcript Release Form

I _____, have read (or have had someone read to me) the entire transcript of my personal interviews in this study, and I feel good that it says what I wanted to say in my interview with Carrie Ann Schemenauer.

I give my permission to Carrie Ann Schemenauer to use these transcripts for her research.

Participant

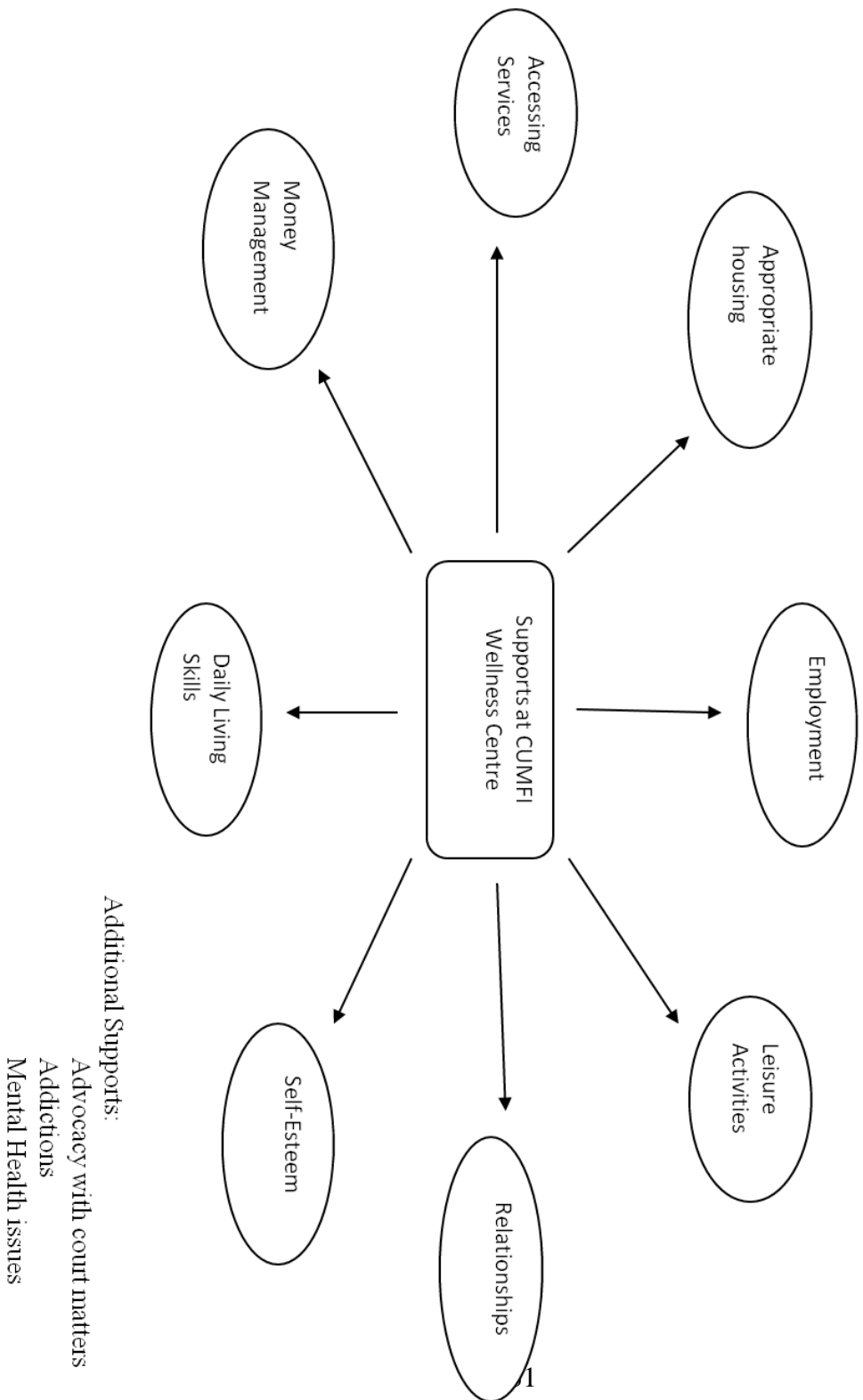
Date

Researcher

Date

Supports Provided to Adults with FASD at the CUMFI Wellness Centre
Saskatoon, SK (2009-10)

Appendix H: Concept Map



Appendix I: Adult Artwork & Writing

July 5th Monday 2010
HATE (So Sedate)
 Fucken hate all the things that you do
 m gonna fucken will you^{all} too
 your gonna get trapped you would not know just what to do
 I'm coming for you I'm coming for you
 HATE is a wonder full thing
 Hate is the malice I bring
 Hate is the only song I'll sing
 So bring the pain to make it rain I'll grow in some
 your all lame ne you blame so I'll fucken take you
 to a place to break you
 we would be all alone it will be your new home
 So call me on my cell phone if you dont want 7 B ab
 Come here ill show you how to fear
 Kill 10 Men to earn 3 red tears
 I'll help you steer clear of the cops
 off with your head as I chop
 your all gonna get dropped
 My voices wont let me go they wont stop
 "chorus"
 Hate you to sedate you I'll take you home just to rape you
 Penetrate me hate me fuck me break me dont say no
 I'm growing crazy about my Angel baby
 Dwaine is a maybe but he got shot like crazy
 + HATE you All I'll do A Fucken Crd 7.61 Rishy

12:20 pm lunch time
12:25 pm lunch time
end
INACELL ^{eye}

Deathmetal
Material
SON

swallowed ~~the~~ broken ~~side~~ so I hide
Hated tears I ~~am~~ cry
Water and Pain Inside
feel me touch me gently
Fuck me tease me Fear me NOW
I want a way outside but I dont know how
Kneeling repenting to God I bow
Running in the yard outside
escaping gently I try
I ~~NEED~~ a way out ~~of~~ of life
Kidnaped & Raped your lie
It is not myself But you who is dead
with a bullet in your heart ~~and~~ ^{with my} gun to your head
wishing softly it was me instead
Down the ~~way~~ alley it is so dark I ~~am~~ flee
Cops are seeing hearing watching me
What is this I see
I am crier you dont know me
Selling coke for three robbing ^{GOD} twenty ³
Now I'm wanted and doing speed too
I am twisted so I would go to your crimes ^{see}
Cocain morphine speed and dopamine &
Needles weed brownie and extracts
fills my head & flows ~~into~~ me
Now I'm in hell in my Hotel that is
this collage ^{It like a} ^{feels} hell it sure is Swell ^{only in} ^{drugs} ^{eyes.}

need \$
to do
add
chorus

3/3

4 → Then I chase him all over the place as he taunts me with his clown laugh (I have never tagged him yet)

- ⑤ F/R's voices saying go to sleep
- ⑥ different voices of guards saying many things
- ⑦ shadow beasts from hell running around the room crawling on the ceiling walls and floor

⑧ A Dead lady in all Black with a Hells Angels bandanna of an eagle riding a harpy with its wings spread its wings are the shape of fire rays. Its eyes are black & red with one (left) white pupil & (right) one pentagram that is orange she is hanging from a slipnot noose holding a dead baby with his head cut off & the babies blood spraying all over the room low east west & high she is telling me "look what you have done to us" the baby represents me and the lady my mother is

9) Over ne ways and you will be with her anyways only if you Repent All your sins & cross over to ~~me~~ ME (In Gods voice soundin heavenly)

10) Infants distress crying (think this one represents me as a baby)

What I see;

1) Swarms of mud wasps attacking me until I have no flesh left cause they rip chunks out of my Body parts

2) Swarms of wasps attackin me with their stingers & biting my face

3) swarms of bees I can see them flying around not bothering me and I enjoy their UIVID Hum

