

**MANEUVERING THE MAZE: EXPLORING THE EXPERIENCES
OF FETAL ALCOHOL EFFECTED ADULTS**

by

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ABSTRACT

Research over the past decade has primarily concentrated on the problems of Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects during infancy and childhood. Currently there are only very limited studies which are concerned with fetal alcohol syndrome or alcohol related effects in adulthood. This qualitative, exploratory study researched the experiences of five adults who have fetal alcohol syndrome or effects. The significant themes which emerged revealed that FAS/E has an impact on cognitive development and self esteem. In addition to this, elements of support were defined by the participants, which lead to directions regarding what helps this population group. This study has particular relevance to social work in that understanding the nature of FAS or alcohol related effects in adulthood, leads to appropriate therapeutic intervention both at a micro and macro level.

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I don't think anybody should drink when they're pregnant, because, like, I see a pregnant woman in a bar, I'll go up to her and I go "Are you drinking?" She's like, "I'm having a beer." I'm like, "You mean you drink?" And I go, "Have you seen me around the bar?" And she'll sit there and says "yeah." And I'm like "do you want a kid to grow up just like me?"

Brenda

INTRODUCTION

Out of 15.1 million alcohol abusing or dependent individuals in the United States, an estimated 4.6 million are women (Cooper, 1991). Specific information regarding the consumption of alcohol by women in the province of British Columbia is not available.

Despite this however, 1991 and 1992 British Columbia statistics do indicate that the average absolute alcohol intake was 9.35 litres per person, 15 years or older, which equals 11 and ½ (750 ml) bottles of wine per person per year (Winqvist, 1995, p.1). British Columbia has the third highest rate of alcoholism in Canada (Single, 1995).

The highest rates of alcohol and other drug consumption in women occurs during the childbearing years (Health and Welfare Canada, 1990). There is no known safe level of drinking for pregnant women (LaDue, 1990). As alcohol is often a recreational drug of choice, the risks become substantial in terms of adverse fetal outcomes. Research during the past decade has substantiated a variation of adverse fetal outcomes when women drink during pregnancy. Fetal Alcohol Syndrome (FAS) is the most serious result of fetal alcohol exposure and is characterized by central nervous system deficits, specific facial abnormalities and growth retardation. When a child or adult has some but not all of the characteristics of FAS, the term Alcohol Related Effects is used, which also contains sub-terms of Alcohol-related birth defects (ARBD) and Alcohol-related neurodevelopmental disorder (ARND), depending on the criteria.

The aim of my research was to look at the experience of fetal alcohol syndrome/effects in adulthood. This thesis has grown out of my work in the counselling field, as well as from

being a foster parent to children with FAS/E. After leaving the field of child protection in order to do family counselling and support, I became acquainted with fetal alcohol syndrome. At that time I had virtually no understanding of this disability. Having direct contact with FAS children and adolescents, as well as their caregivers, I became aware of a wide range of behaviours which were creating exhaustion and frustration for both the child and caregiver alike. My curiosity about the disorder began to grow.

I began to study the syndrome more closely, largely out of my own frustration and feelings of helplessness in terms of helping parents and foster parents deal with their children. One of the adoptive parents to whom I had been providing support, expressed frustrations and fears for her two teenage fetal alcohol affected children. She asked me questions about their future potential that I could not answer. It was at that moment I suddenly realized that these children grow up. Questions began to emerge: What happens when these children grow up? What are they able to do? What are they like as parents? What about their caregivers....how long will they be required to remain responsible for their children? Those questions lead to a closer examination of my caseload as I began to realize that I was also possibly dealing with parents in my clinical practice who themselves were affected by this disability. I began to think about some of my adult clients who were the children of alcoholic mothers. Indeed, the difficulties which they expressed to me, and how they expressed those difficulties, were certainly similar to the difficulties I saw play out in the behaviours of some of the fetal alcohol affected children with whom I worked.

With my new questions about fetal alcohol syndrome/effects in adulthood, I began to seriously question the therapeutic model with which I was working. One of the assumptions

which I had developed in regard to some particular clients was that these individuals were somehow “lacking insight into their behaviours” or, were simply “not motivated or committed to making changes”. As I reframed these assumptions in the light of fetal alcohol syndrome/effects, even though there was no confirmation of the disorder, certain dynamics of these clients began to make sense. Reviewing my experience as a former child protection worker, I thought about some of the clients involved with the Ministry of Social Services. The typical caseload of a social worker who is employed by the Ministry inevitably contains multi-generational families to whom varied and long-standing service interventions have demonstrated little success in terms of stabilizing the family and/or assisting the parents change abusive or neglectful styles of parenting. My own experiential evidence was that often the misuse of alcohol had some role in terms of some of these families coming to the attention of Family and Child Services. I believe that a closer look at current treatment interventions, as well as these type of families is required, as these families seem to remain involved with the Ministry perhaps for several generations. Given the dynamics of alcoholism within many families and within western society, an important factor may be left out by Social Services and their contracted therapy services; that possibly service intervention may be unsuccessful with these parents because there has been a lack of consideration that these parent groups could be disabled by FAS. If this is the case, then counselling interventions contracted to work with these families are missing a fundamental dynamic which influences outcome for these families. There are very few professionals in the field of social work that even consider the issue of fetal alcohol syndrome/effects as possibly relevant to some of their adult clients. I was certainly one of those professionals who did not consider the issue of fetal alcohol syndrome/effects to be relevant to my practice as a child protection worker. Currently, the Ministry of Social Services continues to

lack a working framework or model around the issue of fetal alcohol syndrome and alcohol related effects in respect to both adults and children.

Given these dynamics, and the numbers of families referred by the Ministry to the agency for which I worked, I determined that I required further education around FAS/E. I attended a workshop put on by SNAP (Society for Special Needs Adoptive Parents). This workshop addressed the issue of fetal alcohol syndrome and the teenage delinquent population. Given this older population group, I found that some of my hunches were confirmed and certain questions were answered. However, I found myself quite depressed during my attendance at that workshop because the outcomes seemed so hopeless. I began the process of thinking that more information had to be available in terms of FAS as it effects adolescents and adults, but as I searched, I became aware that there was little available data to help me understand the behaviours beyond puberty.

As a foster parent, I am currently faced with the challenges fetal alcohol syndrome or alcohol related effects brings on a daily basis via the provision of care to foster children in our home. The behaviours which have to be managed are difficult and exhausting, not only for myself as caregiver, but also for the child struggling to sort out his/her world through the maze of fetal alcohol syndrome/effects. Some of the more difficult behaviours I must deal with as a foster parent to children in our home, who have been affected by this disability, are perseveration, lack of organizational skills, poor memory and peer difficulties. I often wonder and worry about their future in light of their difficulties. Yet, every morning is a new day with these kids in my home, as they seem to have an incredible tendency to bounce back with a type of bubbly enthusiasm which defies me in light of the previous day's

difficulties and strains.

Since 1992, I have been on a journey to discover answers to the many questions I have had in regard to fetal alcohol syndrome and alcohol related effects. This research project is part of that journey which still continues. The aim of this research was to look at the experience of this disability in adults. By doing a qualitative study, I felt that I would discover more in-depth answers. Most of the research has focused on the effects of prenatal alcohol consumption on infants and children. Data on FAS/E in adults is very limited, with experiential data even more scarce. Streissguth (1991) demonstrates that fetal alcohol syndrome and other alcohol related effects, are not just childhood disorders, but present areas of difficulty throughout adulthood.

It is my hope that this paper articulates the urgent importance of understanding this disability. This study is significant for social work practice because often an underlying fetal alcohol diagnosis is not considered and/or overlooked. If this happens, intervention is less than effective and the client misunderstood. Efficient intervention with adults who have fetal alcohol syndrome or alcohol related effects cannot take place without an accurate identification of the etiology of the problem. As well, until there is a theoretical base and model for practice in this area, macro levels of intervention will be non-existent or inadequate. The writing of this paper has been personally very meaningful, and I hope that the contents will be beneficial to others.

Chapter One presents a literature review which enables the reader to have a succinct working definition of fetal alcohol syndrome and alcohol related effects. It reviews a

historical perspective of FAS which includes references to women and alcohol abuse.

Framed within a feminist perspective, chapter one acknowledges the necessity behind a research project of this type.

Chapter Two discusses methodology, and provides a rationale for the use of qualitative research methods. The research design of this project is presented. Hermeneutics and Feminist Theory are presented as the two schools of thought influencing my research design. Within this context the overall strategy and conceptual framework is specified.

In **Chapter Three**, I present the findings which emerged as significant for this research project. The findings represent the voices of the participants as they shared with me certain aspects of living with fetal alcohol syndrome/effects.

Chapter Four represents a discussion of the relationship between the findings and the existing body of literature. Implications for policy and practice are reviewed. Limitations of this study and considerations for future research are presented.

Finally, **Chapter Five** dialogues the conclusion of this project and positions some of my concluding reflections.

CHAPTER ONE: LITERATURE REVIEW

Introduction

During the past two decades in particular, the field of medicine and social work has searched for effective and comprehensive interventions to deal with the problems alcohol use generates. There has been an increase in the numbers of individuals identified as abusing alcohol or suffering from the ramifications of a significant family member's substance abuse (Abbot, 1995, p.258). Alcoholism is a disabling condition with life-long consequences to the individual, the family and the community. Alcohol is the nation's recreational drug of choice, yet its misuse creates and accelerates problems of violence, neglect, suicide and poverty. In addition to this, research during the past two decades has demonstrated with increasing clarity, the devastating relationship between alcohol consumption during pregnancy and damage to the fetus. Thus the current most profound effects of alcohol consumption is now being recognized in children. The medical/science field has established conclusive evidence that prenatal alcohol exposure poses a tremendous threat to the health of an unborn child (Little & Streissguth, 1982; Smith, 1982; Jones & Smith, 1973; Hanson, Streissguth & Smith, 1978; West, 1986). The resulting impact is varied and complex, creating physical and neurological impairment.

Social work practice is a discipline with a dual emphasis on policy and clinical practice. Given this, and inherent within the issue of FAS, are dynamics which require exploration at the micro, macro and meso levels. The experience of alcohol abuse in western society and the consequences of FAS/E are embedded and contextualized within behavioural, institutional, and cultural constructs. In order to understand the fuller perspective of FAS, it

is necessary to take a brief look at the historical background of alcohol's misuse involving women and infants.

A Historical Overview: Alcohol, Women and Infants

Since the 18th century in North America, alcohol consumption has played a role and has been a routine feature of society. Estimates of alcohol consumption have been available since about 1790 where per capita, alcohol consumption averaged just under six gallons per year (Kyvig, 1985, p.7). Drinking alcohol was and continues to be a part of western culture. Beer and wine are a natural part of social and family activities for many individuals in North America. Therefore, alcohol's role while not without debate, remains fixed and rooted.

Throughout history in many parts of the world, women's misuse of alcohol has been viewed as being more deviant than men's and less socially acceptable. There have been different time periods during which women's consumption of alcohol was accepted, however, throughout all periods of history, more often than not, female drunkenness was not socially tolerated. In terms of women's drinking during pregnancy, an examination of history reveals that the adverse effects of maternal alcohol use on the developing fetus have been known empirically throughout time and culture (Luke, 1990, p.32). The debate about women and drinking during pregnancy would rise and decline throughout various points of history. Plant (1985) presents a comprehensive review of the historical and general literature which demonstrates that concern about alcohol consumption during pregnancy has been noted for hundreds of years. Attention to the problems alcohol generates to the fetus, was evident during the time of the ancient Greeks. Aristotle charged that "foolish, drunken or harebrain

women for the most part bring forth children like unto themselves, morose and languid” (Johnson, Reeves & Jackson, 1983). Plato stated that “Children shouldn’t be made in bodies saturated with drunkenness”(Burton, 1906, p.26 in Plant, 1985). Sparta, directed their young freewomen to abstain from any wine at all so that they could breed “robust and sturdy” Spartan children (Sandmaier, 1980). The ancient city of Carthage forbade the consumption of alcohol to all male and female newly weds under the age of thirty in order that “defective children might not be conceived” (Haggard, 1942, p.210 in Plant, 1985). The ancient Greeks then, may have been the first to take note of fetal alcohol syndrome, however, they rarely shifted the focus of their concern from the baby to the woman herself (Sandmaier, 1980, p.26).

Later on in history, the “gin epidemic” of London during the first half of the eighteenth century saw children dying in record numbers due to the gin being transmitted prenatally (Sandmaier, 1980). Infants born to alcoholic mothers were noted to have a starved, shrivelled and imperfect look (Dedam, McFarlen & Hennessy, 1993, p.30). Sandmaier (1980) elaborates:

parliament lifted nearly all restrictions on the making and selling of domestic gin in 1701 in hopes of increasing local revenues. As a result, cheap and often badly adulterated gin flooded the country, doing its worst damage in London’s slums. Between 1700 and 1750 the population of London actually declined and children especially were dying in record numbers. Between 1730 and 1749, three out of four children christened had died before the age of five. Since no serious epidemic had swept through the city during that period and since the standard of living for London slum dwellers was actually rising, if very slowly, gin seemed the most likely cause of the deaths. And, if babies were dying of too much gin, whose fault was that? Suddenly public attention focused sharply on the alcoholic mother of London’s slums. Amid cries of ‘bad mother’ and ‘debauched woman’, she became the scapegoat for a national

scandal for which she bore little responsibility and from which she suffered as acutely as did her children". (p.31)

Despite the sociological factors of the gin epidemic, mother blaming was the event of the day, as alcoholic women were scapegoated and raged upon because of alcohol related deaths of their infants. These women existed in desperate poverty, yet concern for their suffering and social conditions was essentially non-existent.

Ironically, in colonial America at this same time, alcohol was seen with positive regard and considered both a medication and social beverage which women could partake.

Regardless of a woman being pregnant or not, participating in an active consumption of alcohol occurred without any real negative objections, until about the early part of the 19th century.

In early 19th century America, alcohol was viewed with greater disdain and blamed for poverty. Jane Addams, the "mother" of much social work practice, concluded the poor would be better off without alcohol as she saw its influence on "exacerbating poverty abuse, inefficiency and political corruption" (Kyvig, 1985, p.9). Thus, alcohol was viewed as a threat to common morality, and a crusade against the problems of alcohol gained steady momentum until the national prohibition movement of 1920. At this point, retaliation against the effects of alcohol on the family as a whole, influenced a reduction in the amounts women drank. However, it should be noted that alcohol abuse among the urban poor women continued (Sandmaier, 1980, p.41).

As women gained new freedoms, particularly following the beginning of World War II,

alcohol invaded the world of women in greater measures. Coincident with the increase in post-war alcohol consumption, a resurgence on the subject of alcohol use during pregnancy occurred during the 1960's (Plant, 1985, p.24), with discoveries leading to a link between maternal drinking and fetal harm. In America, the dismissal of the serious nature of pre-natal alcohol consumption would decrease as new research gained momentum, acceptance and eventual publicity.

Towards a Feminist Perspective of FAS: The Issues of Stigma and Gender

Currently, there are an estimated 28 million adults and young people who have grown up in a family with one or two alcoholic parents (Brown, 1992, p.3). These numbers could be underestimated given the invisible nature of alcoholism in women. Women alcoholics are significantly more likely to isolate themselves than male alcoholics (Van Den Bergh, 1991). This tendency to isolate is likely because historically and currently, society as a whole views the alcoholic as "weak", but a woman with alcohol problems is viewed with even greater disdain than the male alcoholic. Patriarchal society (which has imposed a definition of women) tends to equate a woman's abuse of alcohol with the threatened abdication of an imposed social role and identity. Thus the prevailing trend has been to stigmatize or punish the alcoholic female, rather than assist her (Sandmaier, 1980). The fear that a woman may abdicate socially constructed roles, lends itself to the creation of stigma around women's consumption. This stigma creates barriers to treatment.

An example of this stigma is evident in the issue of alcohol consumption during pregnancy. Clemmons (1985, p.78) states the following:

Further moral censure of the female alcoholic came from the recognition of fetal alcohol syndrome. Attention was focused away from the alcoholic woman and on to her offspring. Identification of this disorder led to continued disparagement for having neglected the unborn child rather than increased understanding of the physical ravages of alcohol abuse on both mother and fetus. Female alcoholism again became a moral issue rather than a socio-medical problem in need of comprehensive treatment. Little attention was given to the emotional concomitants of bearing a child with FAS....As is frequently the case, concern about women is focused on what she does rather than who she is. The concern is for her effect on society in a moral arena or a maternal arena; it is not the woman as a person who is valued but rather the role she is fulfilling for society.

Stigmatization of female alcoholics creates stereotypes which generate isolation and a shame based self. The stigma for an alcoholic mother is even worse, particularly in the light of the knowledge available on drinking during pregnancy. Any "collective cultural condemnation" (Malbin, 1995, p.5) of alcoholic women will only lead to further discomfort in disclosing the extent of their problem. MacPhee (1992) states "many pregnant women who are using alcohol and drugs will not seek medical attention during their pregnancy because they fear a possible apprehension of their newborn baby if they are identified as an alcohol and drug user" (p.66). Hence, stigmatization and blame maintain barriers to treatment, increasing risk for both mother and child, and hindering prevention efforts around FAS/E.

Research has demonstrated the direct link between the consumption of alcohol during pregnancy and various adverse fetal outcomes, however it should be noted that FAS/E is not just a woman's issue but includes the father as well. Some current research literature suggests that we are overlooking the role of gender issues. Schroedel and Peretz (1994) emphasizes that fetal abuse cannot be isolated to maternal alcohol abuse:

The current debate about fetal abuse almost exclusively deals

with problems due to maternal substance abuse....In what is still a generally patriarchal culture, childbearing and rearing are seen as primarily a female responsibility, while providing for the family's economic well-being is primarily a male responsibility. It follows from this basic division of labor that if harm should come to the fetus or child, one's first instinct is to look to the party primarily responsible for its health—the mother.a skewed definition of fetal abuse focuses almost entirely upon socially inappropriate behaviors of the mothers while ignoring the equally pernicious actions of their male partners.

Gender then, is a variable which requires primary consideration in terms of the dimensions of alcohol consumption and FAS/E. The current narrow focus on women excludes the responsibility of the father. Very recent research is beginning to clarify the effects of paternal drinking prior to conception (Friedler in Malbin, 1995, p.5). In case studies of FAS where information is available on the father, the father has been described as a heavy drinker or alcohol dependent (Canadian Centre on Substance Abuse, 1994,p.3). This points to the fact that the exclusive focus on maternal roles in regard to FAS/E is not adequate and reveals gaps in research. A comprehensive approach establishes the necessity of studying adverse birth outcomes beyond the current focus on maternal causes.

Tension is inevitable between the issue of personal responsibility and the societal pressures resulting in addiction. The literature points to a diversity of problems which encompass all aspects of women's lives in regard to the misuse of alcohol. FAS/E is not simply an issue of maternal alcohol abuse, but a complex issue rooted in the underlying social and economic conditions which influence all aspects of maternal and fetal health (Canadian Centre on Substance Abuse, 1994, p.3). A gender-inclusive analysis of the causes of FAS/E redefines the problem and diminishes gender biases (Schroedel and Peretz, 1994). Therefore FAS/E cannot be viewed apart from a feminist perspective, where societal implications and the special needs of women are fused, thus impacting the issue of fetal alcohol syndrome. It is

through the lens of feminism that fetal alcohol syndrome and alcohol related effects is holistically understood and effective intervention secured.

Alcohol Related Birth Defects and Maternal Drinking: A Feminist Perspective

For many years the nature of alcoholism has been studied in men who comprised the majority of research subjects, and the conclusions transferred to women. Traditional beliefs enforced the concept that alcohol addiction was a man's problem thus male subjects constituted the norm in alcoholism research. For several decades research on alcoholism tended to either ignore women entirely or assumed that components of alcoholism was the same regardless of gender (Wilsnack and Beckman, 1984). Therefore little was known or understood about the impact and extent of alcohol on women's bodies. As a result, not enough is understood about the female alcoholic and thus female alcoholics have not received their share of resources, particular to their needs (Rhodes and Johnson, 1994). A lack of available, successful interventions for alcoholic women may hinder recovery, and place women at risk for continued drinking during pregnancy.

Feminist research literature has increased awareness of the different dimensions of the problem of alcohol among women (Abbott, 1995, p.258) and confirmed that women with alcohol problems must be studied as a distinct population (Lester, 1982). A feminist view of fetal alcohol syndrome, includes an understanding of the misuse of alcohol for women as part of a larger constellation of issues. Feminist social work with women who are alcoholics embrace the knowledge that the misuse of alcohol occurs in a social/cultural context that includes poverty, violence, racism and sexism. An overview of the literature pertaining to

women and alcohol, reveals certain complex patterns particularly related to women and their abuse of alcohol.

Finkelstein (1990) developed a list of 14 treatment issues both social and personal, which appear to cause and support women's addiction to alcohol; guilt/stigma, a sexualized image, low self-esteem, feelings of powerlessness, relationships in women's lives, care and needs of children, family violence, sexual abuse/incest, multiple addictions, economic/vocational issues, drinking and pregnancy, anger/depression, eating disorders, and physiological considerations (Rhodes and Johnson, 1994, p.151). Thus a framework of alcoholism treatment which is centered on men is inadequate. A feminist perspective grounds the issue of alcoholism for women within the context of societal/power inequalities.

A feminist perspective then, considers gender, gender socialization and the nature of power constructs in society as critical to the identity and self worth of women. Men and women experience the world in different ways. Some of these differences are visible through coping styles, emotional expression, decision making processes, and values. Men tend to attribute problems to external factors instead of themselves, whereas women tend to blame themselves when something goes wrong (Van Den Bergh, 1991). This internalization process of blame makes the issues pertaining to gender an important factor when treating female alcoholics and when considering the issue of fetal alcohol syndrome/effects. A social atmosphere of judgement only leads to feelings of guilt generating a further cycle of self-blame and alcohol abuse, regardless of the ramifications to both mother and fetus.

A feminist perspective acknowledges that a hierarchical dominant-subservient relationship

between men and women is developed and sustained within the context of our cultural beliefs which inherently devalue women. If society oppresses women and if women believe themselves to be innately inferior, their voice is not acknowledged or heard, so they are at risk to developing addictive behaviours. Addictive behaviour is related to having an external locus of control, where experiences outside of the self are sought to give life a sense of meaning and importance (Van Den Bergh, 1991, p.19). Many women who are alcoholic demonstrate their oppression from socio-economic, cultural and gender dynamics by drinking during pregnancy despite adverse fetal outcome. A feminist paradigm would acknowledge the issues of women and alcohol in the larger context of societal responsibility. Inadequacy, shame, victimization and poverty produces powerful feelings of pain and leads many women to misuse alcohol in order to numb the pain, without consideration of the ramifications. Life situations of violence, abuse, poverty, inadequate daycare, and cultural biases contribute to the oppression and lack of value given to women in society. A feminist perspective of treatment for female alcoholics allows a systemic understanding of the female alcoholic within the larger context of the oppression of women. The recovery process is then implemented through interventions which value self-determination, affirms gender socialization in peoples' lives and the interrelation of people with their environments, acknowledges that power does not justify behaviour, emphasizes empowerment by explaining the function of patriarchy in society and families of origin, and generates solutions to reduce powerlessness which is the result of victimization at many levels (Lundy, 1993). It is impossible to consider the prevention of FAS/E in isolation of these issues.

Societal processes, and sociological contexts are then all directly relevant to the understanding and prevention of fetal alcohol syndrome and alcohol related effects.

Currently however, the majority of research on FAS/E, provides a focus on fetal alcohol syndrome which largely ignores the symptoms of larger social problems. The medical and scientific model through which an understanding of fetal alcohol syndrome is usually acquired, presents a narrow focus which most often places emphasis on pathology. This increases the tendency for fetal alcohol syndrome to be viewed in a deterministic manner. The medical model rarely presents an approach which includes a wider lens from which to view the issue of fetal alcohol syndrome or effects. However, a feminist perspective of women's drinking and fetal alcohol syndrome/ effects, includes the understanding that prevention involves the empowerment of women. If empowerment occurs, women are then assisted to make healthy choices for themselves and for the future generations of children they will bear.

What is Fetal Alcohol Syndrome and Alcohol Related Effects

Attempts to assess the relationship of drinking in pregnancy to fetal harm, developed serious momentum during the early 1960's within the medical field. The majority of the literature that has examined the nature of fetal alcohol syndrome and related effects, has emerged from the medical and scientific models of research. These findings will now be presented.

Plant (1985) reviews the history of FAS/E research and notes that clinical impressions preceded and stimulated research in regard to fetal alcohol syndrome. The early research into the association between alcohol consumption during pregnancy and fetal harm was largely retrospective, and because of this, several reports were unfortunately disregarded as insignificant. However, during the 1960's, scientific interest increased in regard to maternal

drinking during pregnancy. Several significant studies emerged during this time period.

In 1967, Dr. Alexandre Lamarche, a family practitioner who studied 1,245 children of alcoholic parents, presented significant observations which included neurological dysfunction, mental retardation, behavioral disorders, genital malformations, facial anomalies and excess infant mortality (Dedam, McFarlane & Hennesy, 1993, p.30). Dr. Paul Lemoine, a pediatrician from Nantes, France, also recognized the multiple effects that alcohol can have on the developing fetus. His research described a distinct and notable pattern of abnormalities in children born to alcoholic women, which encompassed growth retardation, unusual facial qualities, psychomotor retardation and congenital anomalies (Luke, 1990, p.333). This study was well organized and involved 127 offspring of alcohol-dependent parents. At the time, maternal and paternal alcohol dependence was not distinguished, but the children were noted to have a specific cluster of features common to all of them (Plant, 1985, p.25). While this piece of research allowed for the first formal description of fetal alcohol syndrome to appear in scientific literature in 1968, the report by Lemoine and his associates was unpopular. Essentially, when Lemoine's results were first presented, many in the professional community did not take the results seriously. The findings were considered interesting but not believable (Streissguth, 1995).

A crusade against prenatal alcohol consumption did not really begin until two papers published in 1973 by Jones and Smith, which also described the same patterns and confirmed Lemoine's findings. Their work was based upon that of Christy Ulleland, a pediatric resident in a Seattle hospital, who, in 1969, noted a group of infants who were not thriving. All these children had mothers who had been diagnosed as alcoholic. This became

a significant discovery and led to concern about the dangers of maternal drinking during pregnancy. Building on a foundation of Ulleland's discoveries, Jones and Smith in their research, managed to bring the issue of drinking during pregnancy to a wider medical and scientific audience (Plant, 1985, p.26) thereby establishing the seriousness of fetal damage from prenatal alcohol exposure. The term "Fetal Alcohol Syndrome" also referred to as "FAS" was coined, and criteria for defining FAS was standardized by the Fetal Alcohol Study Group of the Research Society on Alcoholism in 1980.

Fetal Alcohol Syndrome (FAS) is a pattern of birth defects found in people who were exposed to alcohol while their mothers were pregnant. FAS is the most serious result of alcohol exposure and is characterized by particular physical abnormalities and behaviours. A diagnosis of FAS is given when the individual has a cluster of three characteristics; growth deficiency, certain craniofacial features (Appendix "H") and other physical abnormalities, and, central nervous system deficits (LaDue, Streissguth & Randels, 1992).

Other researchers, namely Sokol and Clarren (1989) presented the term "fetal alcohol effects"(FAE), which is used when an individual has a history of prenatal alcohol exposure and some characteristics of FAS but not enough for diagnosis of the full syndrome (Streissguth, 1991). An individual who suffers from FAE may not have all or any of the physical symptoms which characterize FAS but will have cognitive and behaviour problems (Streissguth, 1991). It should be emphasized here that a diagnosis of FAE is not a lesser diagnosis, but can in fact have some extremely serious implications as it is a more invisible diagnosis. Watson, (1992) elaborates this:

Occasional episodes of binge drinking or frequent consumption of moderate quantities of ethanol during pregnancy may cause more subtle neurobehavioural impairments in offspring in the absence of the gross morphological and neurological defects associated with FAS. Examples of these more subtle neurobehavioral defects, often described as fetal alcohol effects (FAE) or alcohol related birth defects (ARBD) include long-term impairment of learning, hyperactivity, attention deficit disorder and speech and language disorders. These observations are particularly disturbing because moderate ethanol consumption during pregnancy is more common in society than the level of ethanol consumption required to produce FAS (p.171).

Hissock and Nanson (1990) refer to Streissguth's study which compared the long-term outcome of 58 young adults with FAS to 34 young adults with FAE:

Although the adults with FAS were significantly more impaired intellectually than were the adults with FAE, there were no differences between the two groups in terms of academic or social functioning. Thus the long-term social consequences of FAE may be as severe as those of FAS. (p.656)

In Dr. Streissguth's recently released 1996 Secondary Disabilities Study, six main secondary disabilities were examined in 473 FAS/E participants who ranged in age from 3 to 51 years. Secondary disabilities, such as mental health problems, disrupted school experience, trouble with the law, incarceration, inappropriate sexual behaviour alcohol and drug problems, were explored (Streissguth et.al, 1996). One of the fundamental characteristics associated with a higher level of secondary disabilities was fetal alcohol effects, rather than fetal alcohol syndrome (DeVries, 1996, p.6).

Inclusive within the diagnostic process for FAS/E, are other important factors to consider.

Michaelis & Michaelis (1994) state the following regarding the development of FAS which must be considered when reviewing the issue of alcohol consumption during pregnancy:

Many factors play a role in the development of FAS. Among these are the frequency and quantity of maternal alcohol consumption during pregnancy, the timing of alcohol intake during gestation, the stage of development of the fetus at the time of its exposure to alcohol, the nutritional status of the mother and her intake of other drugs, the genetic background of the mother and of the fetus, and the mother's overall state of health.

Thus, the issue of diagnosis is complex and requires expertise because there is no simple, objective laboratory test for diagnosing FAS. Rather, the diagnosis is based primarily on clinical definitions developed for the purpose of clinical practice and research (Sokol & Clarren, 1989).

More recently, new diagnostic criteria for fetal alcohol syndrome and fetal alcohol effects have been established. These are outlined in Appendix "E". In recognition of the seriousness of fetal alcohol syndrome and related conditions, the U.S. Congress mandated that the Institute of Medicine of the National Academy of Sciences conduct a study of FAS and related birth defects (About FASE, 1996, p.10). The committee studied the previous diagnostic criteria and felt that there were certain inadequacies which required clarification. Thus a more refined diagnostic criteria was established. The diagnosis of fetal alcohol syndrome now includes criteria presented with confirmed maternal alcohol exposure (Category 1), or without confirmed maternal alcohol exposure (Category 2). As well, partial FAS with a history of confirmed maternal alcohol exposure establishes a Category 3. Category 3 diagnosis will be useful for adults who present for a diagnosis (About FAS/E, 1996, p.11). The new category "Alcohol Related Effects" includes what was the diagnosis of fetal alcohol effects but has now become more specific to include the terms Alcohol-related birth defects (ARBD) and, Alcohol-related neurodevelopmental disorder (ARND).

Each term (category) has its own set of detailed criteria. I would like to note that for the purposes of this thesis, the term Alcohol Related Effects, will be used interchangeably with the term Fetal Alcohol Effects because the new diagnostic criteria has just been recently released. However, "Alcohol-related neurodevelopmental disorder" essentially replaces the term "Fetal alcohol effects".

The B.C. Health Surveillance Registry is the formal system in place in this province to track the prevalence of fetal alcohol syndrome and alcohol related effects. Unfortunately an accurate determination of the extent of the problem is exceedingly difficult due to the Registry's voluntary reporting system and the lack of knowledge among health professionals (Loock, 1990 in Winquist, 1995). A centralized registry which could be utilized to study the long-term effects of FAS/E, is not available. Thus, valuable research information and the allocation of resources is hindered.

The B.C. FAS Resource Group states that an incidence rate of 3-4 per 1000 live births is a reasonable estimate for the British Columbia population, with the rate of FAE estimated to be about 5 times higher (MacDonald & Associates, 1990, p.7). In some communities in B.C. and the Yukon, the prevalence of FAS/FAE has been as high as 1 in 5 (Robinson, Conry & Conry, 1983). These statistics, developed from within Native communities, reflect the high prevalence of fetal alcohol syndrome and effects among First Nations and points to the necessity of considering fetal alcohol syndrome within the context of structural issues such as oppression and poverty. FAS is a marker for families and communities in distress (Streissguth, 1988).

FAS/E in Adulthood

The difficulties tracking the prevalence of FAS or alcohol related effects, indicate that there are likely many adults in Canadian society who struggle with FAS/E undiagnosed. The Standing Committee on Health and Welfare in 1992, stated that “the plight of undiagnosed FAS/FAE adults has not received much attention...this is an important aspect of the overall problem and should not be ignored.”

The complexities related to the scientific study of FAS are enormous, however the results are conclusive that alcohol consumption during pregnancy is unsafe. Scientific and medical information, based on research involving animals, infants and children, have revealed that the neurological damage resulting in mental handicaps is the most debilitating aspects of FAS (Steinhausen, Willms, and Spohr, 1993). Prenatal alcohol exposure is one of the leading known causes of mental retardation in the western world (Abel and Sokol, 1986). The research also points to a range of problems in infants and children which includes susceptibility to infection, oversensitivity to touch, attentional deficits, fine motor difficulties, developmental delays, hyperactivity, distractibility, impulsivity, memory difficulties, difficulties in making transitions, poor judgements, depression, lower average IQ performance, difficulties in predicting consequences for behaviours and a tendency to not track or understand abstract concepts (Streissguth, LaDue & Randels, 1988; LaDue, Streissguth & Randels, 1992; Streissguth, 1991; Olson, Burgess & Streissguth, 1992; Watson, 1992).

How FAS/E diagnosed infants and children develop and progress as they grow into

adulthood is a new area of concern (Cooper, 1991). In terms of the impact FAS and alcohol related effects has during adulthood, there are many questions which remain unanswered. Most of the individuals with FAS or alcohol related effects described in the medical literature have been young children, with only isolated case reports of adolescents and adults (Streissguth, 1991). This is an area of research which is just beginning to develop. Long time researcher in the field of FAS, Anna Streissguth, stresses the importance of long-term follow up studies (Streissguth, 1992, p.3). Data on FAS and alcohol related effects in adults is limited because the study of these disabilities is relatively new with little longitudinal research. West, Goodlett & Grandt (1990) state that "in the FAS/FAE population that is now approaching adulthood, we must begin to identify precisely the long-term functional status including preserved abilities as well as functional deficiencies" (p.684). Day & Richardson (1991) state: "More information is needed regarding the long-term development of alcohol-exposed offspring. In addition the scope of these investigations should be broadened" (p.277).

The current literature available in regard to FAS/E in adulthood stems from medical and scientific research. In my estimation, the research on FAS stemming from the medical and scientific field has been invaluable, however there is a need to broaden the scope. Many gaps continue to exist, particularly in the field of social work where there is next to no information available on FAS/E in adulthood. The medical research does not contextualize FAS within societal values, norms and expectations which is crucial to the understanding of FAS/E, in terms of prevention as well as treatment. At present, the quantitative paradigm dominates the current research. The existing body of knowledge on FAS/E has been accumulated through quantitative research designs which rely on standardized measures to collect data, thereby excluding and/or silencing the voices of the individuals who have

FAS/E. The intention of social work practice is to establish models of intervention which have been derived from listening to the voices of clients (Van Den Bergh, 1995,p.xxiii). This then establishes the importance of my study, as there is next to no qualitative work which represents FAS or alcohol related effects in adults.

The literature which does exist, largely points to medical research which suggests that the impact of prenatal exposure to alcohol is long-lasting, raising challenges at each stage of development and continuing beyond puberty (Olson, 1992). Streissguth et al. (1991,p.1961) confirms that FAS presents a predictable long term progression of the disorder into adulthood, therefore, fetal alcohol syndrome or fetal alcohol effects are not just childhood disorders. Most of the behaviours which are evident during childhood, continue on into adulthood. For example, the research of Streissguth, Clarren and Jones, (1985) noted that the hyperactivity components of childhood usually evolved into problems of easy distractibility, inability to attend to relevant data, and an inability to ignore irrelevant information during adulthood.

The Journal of the American Medical Association, in March of 1991, published the first major study of the long-term consequences of FAS (Streissguth, 1991). This study involved the collaboration of researchers from the University of Washington Medical School with other professionals from New Mexico and British Columbia. This study researched 61 individuals ranging in age from 12-40 years, with the average age of 17. Specific types of adaptive behaviours such as failure to consider consequences of action, lack of appropriate initiative, unresponsiveness to subtle social cues and lack of reciprocal friendships, constituted some of the findings (Streissguth, 1991).

Drawing from clinical experience with fetal alcohol syndrome over a 15 year period, LaDue, Streissguth & Randels (1992) present helpful information in another study which was comprised of 92 patients with fetal alcohol syndrome and fetal alcohol effects. Their sample had comprised a mean age of 18.4 years, with the age range, 12-42. Clinical observations, caretaker reports and other measures, documented social and adaptive functioning as the areas of most concern. These researchers found that areas of difficulty which persisted into adulthood were attentional deficits, poor judgements, poor problem solving abilities and impulsivity. They noted a wide range of delays and competencies mostly because of varying intellectual capabilities and suggested that this coupled with the impact of the caretaking environment, create difficulties in predicting future outcomes as adults.

Keeping these factors in mind, Olson, Burgess & Streissguth (1992) present the following general profile of the adolescent and adult individual who has FAS or alcohol related effects:

Adolescent and adult development of groups of individuals with FAS/FAE has been reported only recently....Testing of adolescent and adult patients with FAS found an average IQ in the mildly mentally retarded range, with a wide range of functioning from severe retardation to intelligence within normal limits. Teenagers and adults with FAS or FAE seem to 'plateau' academically and in daily functioning but their problems grow more serious as attention deficits, poor judgment, and impulsivity create obstacles to employment and stable living. Adolescents and adults with FAS/FAE have been described as "innocent", "immature" and easily victimized. They are at risk for serious life adjustment problems, including depression, alcohol abuse, and pregnancy (p.25).

The developmental and cognitive handicaps persisted throughout life, with attentional deficits, difficulties with judgement, comprehension and abstractions creating frequent behaviour difficulties (Streissguth, 1991, p.1). Further research in both rat and human

studies have indicated that mothers who have FAS comprise a very high-risk group as they often have problems understanding the consequences of their own actions as well as those of their babies (Streissguth, 1993, p.4).

Morse, in Rathbun (1993, p.7) is most concerned about the problems of FAS and FAE related to the central nervous system where the actual development of the brain is affected, thus creating information processing difficulties. Morse describes these information processing difficulties as manifesting in three ways: First, there is difficulty translating information into appropriate action; second, there is an inability to generalize information from one situation to another as often information is interpreted very concretely; and finally, there are difficulties perceiving similarities and differences between events. Impact to information processing functions can create all sorts of difficulties in terms of how the individual perceives and relates with their world.

Streissguth (1991) highlights the importance of understanding the variation of problems connected to FAS/E, but emphasizes that "the diagnosis of FAS does not carry with it any particular guarantees or inevitable conclusions about levels of achievement" (p.2).

Streissguth explains that because some degree of brain damage has been sustained, the results of the brain damage will be evident to varying degrees in the person's adaptive behaviours. She further suggests that the more serious manifestations of FAS "may well be experienced at that time in life when the expectations for independent functioning are the greatest" (p.2).

The above information demonstrates the need for further understanding of FAS and alcohol

related effects during adulthood and the necessity of on-going research beyond the medical and/or scientific fields. In order to determine appropriate and efficient interventions with this population group, increased attention towards FAS/E in adulthood is crucial. The field of social work must generate more understanding and involvement with this issue. While the medical literature points to a wide variation of difficulties which emerge when a person has been impacted by FAS/E, gaps in the knowledge base are evident. A review of the literature reveals that there is a lack of information regarding FAS/E from the affected individuals themselves; a lack of knowledge of the opportunities which contribute to significant, sustained success; a lack of practice strategies or a working model of intervention; and, a lack of a broad spectrum of research.

Diagnosis

Fetal alcohol syndrome and alcohol related effects is a medical diagnosis and is best made by a trained dysmorphologist or pediatrician. The issue of diagnosis is an important one when considering aspects of the disability. Identification of persons with this disability is more difficult as they mature (Streissguth, 1991), because the physical features of FAS are less distinctive after puberty. Therefore obtaining an accurate diagnosis or evaluation as early as possible allows for better intervention. Hence, adults with FAS and particularly alcohol related effects, often go undetected. However, failure to diagnose FAS and alcohol related effects can lead to inappropriate treatment interventions, particularly for those individuals who come to the attention of drug and alcohol services, mental health services, or child-protection services. A diagnosis can help explain the cause of the adult's problems and give context and meaning for the presenting difficulties. Social workers have often

encountered individuals in clinical practice who have difficulties progressing towards “emotional health” and stability even though there has been a variety of intensive, long-term therapeutic interventions. When studying and treating the dynamics of alcoholism for example, an important factor may be left out by social services trying to help; that possibly these individuals could have their problems compounded by the disabilities of fetal alcohol syndrome or alcohol related effects. If this is the case, then traditional counselling interventions may miss a fundamental piece which influences the therapeutic work. The standard interventions employed will be continually ineffective. My personal experience suggests that therapists or social workers in relationship with these individuals can easily misunderstand their behaviours and responses and labels such as “not insightful”, “lazy”, “resistant”, “unmotivated” can develop. In essence, prior to the diagnostic and identification process, the individual’s behavioural problems can elicit inappropriate responses from family, their social environment, and from helping professionals (Malbin, 1993). That professionals lack training to identify FAS/E which results in ineffective treatment models, is an issue regarded as particularly problematic (Devries, 1994).

Despite the current increased attention towards fetal alcohol syndrome and alcohol related effects, widespread understanding, recognition and response has been very slow. LaDue (1990) states:

Society is in massive denial about fetal alcohol syndrome. That denial involves not recognizing alcohol as a drug that is proven to cause birth defects, not recognizing the need for education about the syndrome and its prevention, not recognizing the numbers of children and adults who are affected by the syndrome, and not recognizing the need for care of those with the syndrome (p.3).

This denial permeates all aspects of society, including professionals in every field of social service. The gaps are apparent and inclusive of the need for an increase in research and public attention. With an accurate understanding of this disability in adulthood, a reframing of the problems and of the person occurs, allowing for a definition of proactive support to emerge. Treatment and support models can then develop realistic expectations which are helpful rather than helpless.

The consideration of diagnosis must also include an understanding that there is a danger that diagnostic labelling can create or promote further pathology thus dehumanizing the person in distress (Brown, 1994). Research has demonstrated that often the diagnostic label will have negative consequences for the person to whom it is applied (Caplan, 1995). The diagnostic naming puts the client at risk to how they will be perceived and treated. Stigmatization, negative attitudes and discriminatory behaviours have often been the result of a diagnosis. The mentally ill are one example of a population group victimized by the generalized effects of a pejorative label (Page & Day, 1990). If diagnosis does not go beyond the label to a treatment plan, the client has not been properly assisted. It is imperative that diagnosis leads to solutions and a response which defines treatment and prevention interventions without implications of stigma.

Diagnosis as it is commonly practiced, also adds a risk of a power imbalance between the helping professional and the client. Brown (1994) suggests that "in unilaterally imposing a diagnosis, the therapist lays a claim to sole knowledge of the true nature of the client's difficulties establishing the authority and expertise of the therapist in no uncertain terms"(p.138). This problematic aspect of the diagnostic process imbalances power for a

marginalized group of individuals such as fetal alcohol affected adults.

Despite the difficulties inherent within the diagnostic system, failure to diagnose FAS and alcohol related effects can lead to inappropriate treatment interventions and lack of service. Diagnosis relieves the person of having to meet unrealistic expectations (Streissguth, 1991) and removes the tendency to self-blame. LaDue (1990) suggests that diagnosis provides more statistical evidence for researchers and those lobbying for governmental funds which can assist individuals with FAS or alcohol related effects. Diagnosis puts a name and makes visible a problem which society has not been prepared to address.

Community Level Service Issues

Due to the lack of research and understanding about FAS in adulthood, community services for this population group are basically nonexistent. In a document prepared for the FAS Information Services Providers Committee, data collected by nine agencies in British Columbia (Appendix "F") who are commonly recognized sources of FAS and NAS (Neonatal Abstinence Syndrome) information, have identified issues pertaining to youth and adults affected by FAS/E. Some of the issues recently identified, include the following:

1. Research regarding FAS and adolescents/young adults is lacking. Also lacking is a full range of services, and advocacy/support for adolescents and young adults affected by FAS/E. Vocational and lifeskills training are desperately needed.
2. Adults with FAS/E lack services that will support their efforts to live independently.

3. Residential alcohol and drug treatment specific for adolescents and adults affected with FAS/E, are not available.
4. Many health, education and social service providers do not have the training to effectively intervene on behalf of FAS affected youth and adults.
5. Demand for training is exceeding the supply of knowledgeable, experienced trainers available across the entire service sector.
6. The recent Child, Family and Community Services Act has new policy regarding the provision of services to support families in their communities, promised through legislation, but these services are still largely unavailable.

This report, Who's Asking: Measuring Demand in B.C. for information about Fetal Alcohol Syndrome/Effects (FAS/E) and Neonatal Abstinence Syndrome (NAS) demonstrates that the demand for knowledge and understanding about FAS/E is increasing, with issues emerging regarding FAS in adolescence and adulthood. The identified issues point to the gaps in terms of pro-active measure of intervention. The report further states that requests for information regarding FAS (and NAS) during May to October 1996 totalled 3,557 calls to these nine agencies. It is apparent that FAS and Alcohol Related Effects is becoming an area of growing concern.

Rationale for this Research Study

Although the research literature is beginning to develop more of an understanding of FAS and alcohol related effects pertaining to adults, many gaps continue to exist. One of the major aims of my study therefore is to extend the existing body of literature and bridge the

gaps which are apparent. First, there is very little research available on FAS or alcohol related effects in adulthood. Second, most of the existing literature is medical or scientific in nature. While this lens is highly useful and necessary, it is also limited in scope. The medical and scientific lens has a very focused vision on symptomology and pathology. The measures constructed for those types of research include clinical observations, animal studies, caretaker reports, intelligence scales, and other types of testing. Most, do not acknowledge the voices, words and thoughts of the persons who actually have the disability. These traditional approaches do not necessarily present the feelings and opinions of the participants being studied therefore the participants own descriptions of their reality are not heard. This gives an assumption that their accounts cannot be accepted as credible.

Feminist qualitative research methods validate subjective experience as a standard of knowledge. It searches for the meanings people attach to their lived experiences with in-depth open ended interviews stressing the importance of the participants' perspective. It is the intent of my research, as an exploratory, qualitative study utilizing feminist principles, to understand FAS/E in terms of the participants lived experiences. The current literature demonstrates the dominance of medical research pertaining to FAS/E. We have very little understanding as to the practical strategies necessary to assist this population group, particularly in the field of social work.

This study was designed to hear the voices of fetal alcohol affected adults who have a disability which has largely remained invisible and misunderstood. My intent was to go to the participant as the source of expert knowledge, which is congruent with the social work principle of starting where the client is. I wanted to understand what life is like living with

FAS/E in adulthood. It was an opportunity to validate these adults' subjective experience of fetal alcohol syndrome/effects and develop more insight into their lives.

CHAPTER TWO: RESEARCH DESIGN

Methodology

This chapter describes the research design of my study. This qualitative, phenomenological study, utilizing principles from hermeneutics and feminism, explores the life experiences of five adults who have fetal alcohol syndrome or alcohol related effects. Given that the focus of my study was to explore the meaning that adults who have FAS/E construct from their experience of FAS/E, it was appropriate to employ a qualitative design. As well, there has been virtually no qualitative work done in my chosen area of study, so this also informed my rationale for doing qualitative research.

A qualitative research study allows for an understanding of life experience from the perspective of the participants (Moon, Dillon & Sprenkle, 1990; Morse & Field, 1995), by putting them into the position of 'expert'. Social work practice involves the principle of "going to where the client is" (Malbin, 1993), thereby allowing their subjective experience to be seen as both credible and valid. It is the interactive approach of qualitative research which allows myself as researcher, and consequently the audience, to develop a deeper, more detailed understanding of the participants' lived experiences of fetal alcohol syndrome or effects. The components of qualitative inquiry involves analyzing data which contains detailed descriptions and direct quotations from the participants in a study, which capture their personal perspectives and experiences (Patton, 1990). To do this effectively, qualitative analysis is "equipped to cycle back and forth between variables and processes demonstrating valuable connections" (Miles and Huberman, 1994 in Coffey & Atkinson, 1996, p.143). My knowledge of fetal alcohol syndrome in adulthood develops deeper meaning as it is

constructed further via the interchange of views between me and the participants as emphasis is placed on their understandings of their experience. This mutual interaction and verbalization within qualitative research, allows for an information rich presentation of the phenomenon being studied.

The vast majority of fetal alcohol research is medically or scientifically based and quantitative in design. Given that fetal alcohol syndrome or alcohol related effects is not well understood in adults, the employment of a qualitative method discovers important variables, events, beliefs, and attitudes which provides opportunity for an in-depth understanding of adults who have fetal alcohol syndrome (Marshall & Rossman, 1995). For my research, I felt that a qualitative study was a less restricted way of understanding fetal alcohol syndrome and the resulting broader understanding would generate further knowledge in terms of what needs to be explored in future research, thus assisting the provision of services for this population group. A comprehensive, interactive exploration of lived experience can add to the limited existing knowledge base in the field.

Understanding how my own experiences and assumptions contributes to or informs my research is of major importance. Who I am influences what I hear. Positioning myself in my research project involves an examination of my values. In order to make this explicit, the next section of this chapter brings a focus to my conceptual framework. Kirby & McKenna (1989,p.25) state that "what knowledge we are able to observe and reveal is directly related to our vantage point....different methodologies carry with them specific underlying assumptions which will shape the way information is gathered and the kind of knowledge created". Hence, two schools of thought, hermeneutics and feminism, are two perspectives

that most informed and influenced this qualitative research project. In order to define more clearly the positioning which I brought to this research process, I will elaborate on those aspects of hermeneutics and feminist theory which were integral to the design of this project and influenced the methodological process.

Hermeneutics

Hermeneutics, as a branch of phenomenology, is a strategy of inquiry that can be treated as both an underlying philosophy and a specific analytic process (Bleicher, 1980).

Hermeneutics constructs the philosophical base of interpretive research that attempts to understand phenomena through the meanings that people assign to them. In essence, the interpretation of meaning is the central theme of hermeneutics. It's thrust involves having in-depth conversations, which are initiated by asking questions about what it is like to have a certain experience. The methodology of hermeneutics is descriptive because it aims to let things speak for themselves, and it is interpretive as well because the facts of lived experience are always meaningful and able to be captured in language which interprets it's meaning (VanManen, 1990, p.180). The researcher embarks on a quest for knowledge of the phenomenon being studied via a continual process of in-depth questioning, checking and reflecting. Through this process, increased insights into the meaning the research participants construct regarding their lived experiences occurs.

Several assumptions guide the hermeneutic approach and lay out the foundation for its methodology. The purpose of my research was to learn how FAS adults experience their everyday lives. In order to discuss my understanding of the aspects of hermeneutics which

informed and guided my research process, I will now present definitions which succinctly outline the assumptions and practices central to hermeneutic research as outlined by Kvale (1996):

1. Hermeneutics elucidates the dialogue represented within the interviews, to be interpreted, in order to discover the intended or expressed meaning, allowing for both a descriptive yet interpretive process (p.46).
2. The process of analysis is characterized by a hermeneutical circle, a back and forth process between the parts and the whole that allows for a gradual deepening understanding of meaning.
3. The interpretations of the interview stop when the meanings of the different themes which have emerged through the process of uncovering, lead to patterns which make sense (p.48)
4. There is a testing or a comparison process, of the interpretations of single statements and the global meaning of the interview via a constant questioning attitude towards the data (p.48)
5. Interpretations focus on the content of the statements as the researcher tries to understand the expressed life world of the participant. The researcher is immersed into the world of the participant (p.49).
6. It is expected that the researcher have extensive knowledge of the theme being explored in order to be sensitive to context and nuances of meanings expressed (p.49)
7. The research process includes a consciousness about one's own presuppositions and stands ready to acknowledge and understand them during the analytic process (p.49).

The intent of my research was to hear the voices of the participants and their view of fetal alcohol syndrome as it played out in their every day lives. The hermeneutic process allowed me to achieve a deeper understanding of the participants' lived experience primarily through its circular, continual questioning process which harnesses several perspectives of the data. While the researcher is immersed in the data, the circular process connected to hermeneutic interpretation attempts to make sense of the whole, while reflecting and questioning the parts of the whole. Themes develop as each part of the text is discerned in light of the text as a whole, taking into account the participant's circumstances as well as the larger social picture. Making sense of the data in this fashion enables a research process which, gives recognition to inter-subjective knowing, validating the phenomenon as described (Van Manen, 1990, p.11) while inclusive of the researcher's own interpretation, insight, impressions and questions. From a hermeneutic perspective, it is assumed that the questions I asked my participants determined what I found out, and those questions carried within them my presuppositions. My interpretation of the data then plays a critical role in terms of the research. The voices of the participants are heard, reflected upon and validated throughout the entire research process, however, the hermeneutic mode of analysis brings forth my own understanding and sense of their story.

Feminist Methodology

Hermeneutics is a process of interpretive inquiry that provides a way of asking questions, while feminist methodology provides a lens with which to do the questioning and some of the research principles which I incorporated into the design. Both hermeneutics and the feminist approach are focused on the definitions people give to their lives and attempts to

explicate those definitions which are embedded in lived experiences. Feminist methodology compliments and further develops the ideas grounded in hermeneutics.

There are many facets to consider in terms of understanding the underpinnings of the feminist perspective within research. Therefore, I will present those features of feminist theory which provided the analytic lens through which I interpreted the data. These features are incorporated in the following explanations:

1. Feminist research describes the everyday experiences of individuals, especially those on the margin and uses qualitative methods to validate feelings and activities that have been ignored or devalued in traditional research (Cancian, 1991, p.626)
2. Feminist research presents a world view which is concerned with inequality: people and groups who are marginalized. Research activities are then seen as valuable when they are organized to enable a voyage of empowerment for the participants.
3. Differences and diversity are respected and given a voice. Individuals are experts about their experience and subjective experience is credible data. It is respected that life experiences structures one's understanding of life (Swignoski, 1993, p.175)
4. Feminist methodology involves listening to many ways of knowing, centered and located within diverse experiences of the participants, and, co-created through relationships that are reflexive and inter-subjective(Van Den Bergh, 1995,p.xxxiv)
5. The assumption within feminist research is that values influence every aspect of the research process from the questions that are asked to the analysis of the results (Van Den Bergh, 1995, p.xxiv)
6. Feminism allows for conversation in research which is interpretive, critical and partial

(Haraway, 1988, p.589)

7. Issues and experiences particular to human interactions are not viewed in isolation, but seen as part of a social and cultural context. Individual issues are a manifestation of social/political/cultural issues.

The research that is currently available on fetal alcohol syndrome tends to pathologize and center specifically on symptomatology rather than looking at the totality of experience. Information on adults who have FAS is limited to methods of inquiry which retrieve answers through a medical and scientific lens. These non-subjective measures through which most of the research is being done, have tremendous relevance, but creates a sense of isolation and further marginalization for this population group. The feminist lens includes a theoretical foundation which addresses the social context of fetal alcohol syndrome or alcohol related effects. In this study of fetal alcohol syndrome, a feminist perspective assists in creating an understanding of the person behind the diagnosis, and attempts to empower that person to bring forth their voice of experience. In my research study, by asking the individuals who are affected by FAS/E questions about their own experiences, I hear their voices, their perspective and understanding, thus clarifying or decreasing “knowledge distortions based on stereotypes” (Van Den Bergh, 1995,xxviii). The interview format was semi-structured, scheduled in accordance to what suited the participants best, and allowed for interaction based on a mutual discourse. One of the distinctive features of feminist social work is it’s incorporation of a two way interactive interview which values the participants as collaborators in the research process (Allen and Baber, 1992) thus empowering participants who could be marginalized, to assume a position where they are experts. I developed this study from a position of understanding that the voices of the experts (those who have

FAS/E) are rarely heard. My position was that of a learner, therefore, my interaction and collaboration with the participants intended to honour their expertise. As I developed my understanding of FAS/E in adulthood by checking and re-checking with the participants the meaning of their experiences, their day to day reality was placed in the center of the research (Swignoski, 1993, p.171). My recognition of their expertise, establishes their power, thus generating the potential of change, at a personal level and social level which is inclusive of myself as researcher, the participant and the eventual readers of this study.

Feminist research attempts to validate feelings and activities that have been ignored or devalued in traditional research (Cancian, 1991, p.626). This process is inclusive of the researcher's commitment to self-awareness, that the research questions contribute to the empowerment of the participants, and that somehow efforts are made so that the research will indeed benefit the population group it represents. In keeping with this, feminist methodology is not detached or value free (Cancian, 1991, p.626). Therefore, as the researcher's point of view is an integral part of the data, the issue of reflexivity must have an important place during the research process. Swignoski (1993) stresses the importance of reflexivity in research through the researcher's awareness of their position.

To ensure reflexivity and credibility within the research process, the subjectivity of the data is managed by making explicit any bias on the part of the researcher. Therefore, it is important that I acknowledge the values and standpoints which I have brought with me into this research project. My familiarity with the literature, and my experiences working with FAS children and adolescents, have informed my perceptions of FAS adults. I expected that I would encounter difficulties with cognition and I was aware that I needed to be conscious

of how this assumption would impact my research. To this research study then, I have brought with me beliefs that the individuals who have lived through the experience of fetal alcohol syndrome, have credible voices, but that there may be difficulties in interpreting those voices. I also believe strongly that in order to understand the full dimensions of the syndrome, fetal alcohol syndrome cannot be viewed in isolation of societal responsibility. I acknowledge that my beliefs and experiences inform this research, however my approach within the research process is that of a learner, whereby I am educated by the participants in terms of the meanings which they have constructed around fetal alcohol syndrome and effects. The participants stories and perspectives, informed, guided, directed, and expanded my beliefs. The thrust of feminist research involves being informed by listening to the many ways of knowing which is centered and located with the experiences of the research participants (Van Den Bergh, 1995, p.xxxiv) and that this process is framed within the mutual, interactive and reflexive relationship of researcher and participant. It has been my intent throughout this research process, to have this reflected in the design of this project.

Sample

The study of fetal alcohol syndrome and effects in adulthood is new. Because of this the identification of FAS/E in adults is not an easy task due to the lack of knowledge and expertise in the field. Patton (1990,p.169) states that “qualitative inquiry typically focuses in depth on relatively small samples, even single cases”. The participants selected for this study were more purposive rather than random (Miles and Huberman, 1984, p.27). The original plan of this study was to interview eight mothers who had a diagnosis of fetal alcohol syndrome, and, who were currently parenting. This was a deliberate choice as the

literature had very little to say on this population group except that they and their children were very high risk (Streissguth, 1991). This choice also occurred because part of my social work background involved experience doing child-protection social work and I viewed that qualitative research with FAS mothers could present a wealth of information much needed in the field. I had expected that the participants would have to come from a variety of settings. Unexpectedly, the process of connecting with various individuals who were in positions to assist me with my recruitment, resulted in my acquiring information about the ongoing needs for service in regard to FAS adults, but, one dead end after another in terms of locating participants whom I could interview. I attributed this to the fact that part of my criteria was that the participants have an actual diagnosis of the disability. Establishing this criteria was intended to enable further credibility of the data. As well, I was very interested in the whole process of diagnosis. However, because of this criteria, and because my decision to have the participants as mothers only, the procedure of recruitment became very difficult and extremely frustrating. I attempted to abate my frustration by reassuring myself that research on fetal alcohol syndrome in adults was quite new and the difficulties recruiting participants indicated the tremendous need for research in this area. In a discussion with Brenda Copeland, a researcher at the University of Victoria who is also involved in a study on FAS in adults, Brenda stated that there was no experiential information regarding fetal alcohol syndrome in young adults. Essentially what they know and experience in terms of their perspectives and voices being heard, is rarely documented. She also confirmed tremendous difficulties in accessing participants who have FAS for research purposes. She suspected that this was related to the lifestyles of many of these individuals that made them difficult to access.

Based on my own difficulties with recruitment, and, on some of Brenda Copeland's recommendations, I decided to expand my focus to FAS/E adults in general. The criteria for the participants were then as follows: any adult who has a diagnosis of fetal alcohol syndrome or effects, who was over the age of 19 years and willing to participate in the study.

Despite the change in criteria, I still had difficulties recruiting participants. My first step was to approach two organizations who were well acquainted with FAS and work with adults who have both confirmed and unconfirmed FAS. Sympathetic to my plight, and agreeing that the research I was doing was valuable, both agreed to approach tentative participants. However, no referrals came from this strategy. The resulting feedback was that the potential participants felt so marginalized, that they were distrustful and would feel used because research of this nature did not necessarily give anything back to them. Although I knew my study involved research from the margins, the difficulties inherent within this type of research, was incredibly illuminated through the recruitment process. I was suddenly very aware about how easily "knowledge can maintain oppressive relations" (Kirby & McKenna, 1989, p.15) despite my own good intentions. I was faced with a sobering reality. While the main intent (my good intentions) of my research was to assist the individuals who have FAS gain a voice and facilitate a deeper understanding of the issues of FAS for social workers, the potential participants didn't see this as a valuable reality for them. This awareness caused anxiety for me because I truly wanted to gain a better understanding about FAS in adulthood from their perspective and release this understanding to others in the most empowering way possible.

Despite my anxiety, this aspect of the research process illuminated crucial issues regarding doing research with “difficult to research people”. I made every effort to make sure that my research project would represent the participant’s experience, as well as respect their time and effort in talking with me. Part of this included a decision to offer the participants the sum of \$20.00 in recognition of the value of their time. As well, I determined at this point that this research study would be incomplete if I did not make efforts to share my findings beyond the scope of this thesis.

I finally connected with the FAS/E Support Network of B.C. who graciously assisted me obtain my sample of participants. The FAS/E Support Network provides information, support and services for families, professionals and the broader community around prevention, intervention and treatment issues pertaining to alcohol related birth defects (About FASE, 1996,p.3). See Appendix “ G” in order to have a full description of their services.

In my conversation with the FAS/E Support Network staff, (all of whom are raising or have raised children with FAS/E), I explained the purpose of my project and, again, was immediately affirmed about the importance of the project and the difficulties in obtaining participants. The staff volunteered to contact individuals whom they knew as suitable for my research to determine if they would be interested in finding out more about involvement with my study. If the potential participants expressed interest, they were asked for permission to provide their name and phone number to me so that I could contact them directly. This method of recruitment was suggested because of memory and organizational difficulties for some of the potential participants.

A sample of five individuals was obtained through this recruitment process. An additional person was recruited via a snowball effect. Someone who heard I was doing this study was in contact with an individual who was interested in participating. One individual changed her mind about doing the project at the last minute, so the total number of participants dropped from six to five. While my original intent was to interview eight individuals, the difficulties in recruiting participants who had an actual diagnosis and were willing to discuss their experiences, prevented me from increasing the sample size. I must also state that time was a factor as well. Kuzel (1992) addresses the researcher's concern regarding credibility in small sample sizes, but confirms that "good qualitative research is good because it investigates a question that is significant for the investigator, the respondents, and the audience for the report"(p.43). In my research study, the very fact that there is a general lack of research about FAS adults, and therefore not much is known about these adults, invites in and of itself, considerations that this sample size presents information rich opportunities of understanding about the nature of FAS in adulthood. The smaller sample sizes provided an opportunity to "illuminate the questions under study" (Kuzel, 1992, p.33) by intentionally going "in-depth" during the original interviews and then again through re-interviews. Initial contact with the potential participants was by telephone. During the telephone conversation I identified myself and the purpose of my study. On the telephone, I assured each participant that participation was strictly voluntary and that confidentiality would be assured. Every potential participant whom I contacted agreed to take part and expressed that this was because of their desire to help others through the telling of their story. This dimension of my research process helped confirm that the participant can be individually empowered by taking part in research where "the veil of invisibility surrounding their everyday lives becomes less obscured" (Opie, 1992, p.7). This relieved

some of my own initial anxiety as a researcher. To demonstrate my respect for their time, I paid each individual \$20.00 per interview. Three participants were interviewed once, and two out of the five were interviewed twice. The two second interviews took place in order to clarify certain points which were raised in the first interviews, and generate further in-depth understanding.

Data Collection

Measure

The primary data collection method was indepth interviews, which is a data collection method relied on extensively by qualitative researchers (Marshall and Rossman, 1995). The interviews were semi-structured, utilizing an interview guide (Appendix "C"). The purpose of the guide was to allow for a framework from which I could develop further insight into my research question: What are the lived experiences of adults who have fetal alcohol syndrome or effects? The framework for the interview guide was based on my own experiential knowledge and a review of the literature. Patton (1990) suggests that the use of an interview guide assists in focusing the use of limited time but allows for subjective experiences to emerge. The interview guide is a list of questions and probes which maintain the interviewer's flexibility to pursue conversations in depth and to discuss unrelated aspects which emerge during the interview, assuring the researcher a means of probing for a range of needs during the interview (Lord, Schnarr & Hutchison, 1987, p.28) The guide allowed for flexibility so that the data could flow back into it by using the feedback of the participants in regard to the questions asked.

The current literature pertaining to FAS/E adults indicates that these individuals can have difficulties with concentration, distractibility, retrieving information from memory, or, difficulties keeping focused and on track. I was conscious of the neurological impairment created by FAS/E which could be impacting some of the participants, so I wanted to make sure that the questions were worded in a way that would ground the participants in their experience, but not intimidate them. This meant that the questions needed to be simple and concise, facilitating the participants' personal perspectives.

The questions in the interview guide began rather broad based, with the first question intentionally chosen to be as least intrusive as possible. The later questions were designed to explore specifics. My first question was open ended, as it asked the question; "What has it been like living with FAS?" However, after the first interview I restructured that interview question because I realized while typing the transcript that the participant largely focused her conversation with me on the dynamics of fetal alcohol syndrome during her school years. I felt I did not gain enough understanding about what life was like for her as an adult. I realized that I would need to more clearly direct the participants to talk about the effects of fetal alcohol in their adult life so I decided to rephrase the first question from "What has it been like living with FAS to "Can you tell me what it's like living with fetal alcohol syndrome" which is a question which allowed for a greater current reflection of their lived experience, as well as provide opportunity to go into the past. This became a better fit, and in fact I did not always have to utilize the guide as a whole because the participants naturally addressed most of the questions I intended to explore. These considerations and directions enabled credibility and soundness to the means by which the data was collected.

Interview Procedure

The semi-structured interview style which employed the use of open-ended questions, allowed this study to reflect the participants experiences of fetal alcohol syndrome. The interview setting was chosen by the participants and I made every effort to accommodate their schedule. Four of the five interviews were conducted in the participant's homes. The fifth interview was conducted in the office space of the participant's support worker as she felt the most comfortable there. All the settings felt relaxed and had privacy which assured maximum comfort and safety for the participants.

I read both my introductory letter and consent forms out loud. We discussed the issue of confidentiality, and that the participant's name would not appear in the transcripts. Each participant was informed that all the audio-tapes would be heard only by myself and a transcriber and that the only persons having access to the transcript would be myself, a transcriber and my advisor. The consent forms were signed and after some preliminary, and introductory conversation, when the participants felt ready, I turned on the audio recorder. The entire interview was then recorded. While my intent was to keep process notes, I noticed that this was distracting to every participant, so I chose not to do so during the interviews.

After the interviews were completed, and in the privacy of my vehicle, I made occasional notes to record comments which I found particularly striking but were not on audio tape. Other notes on observations also were recorded.

Participants were given as much time as they needed to tell their stories in their own words.

Each interview lasted approximately 1.5 hours. After the interviews were over and the audio-tape turned off, a debriefing time occurred for about 15-30 minutes, in order to discuss how they felt about the interviewing process. None of the individuals expressed any concerns but appeared relaxed and indicated that it felt good to assist.

The issue of establishing rapport was important. The conduct of the study often depends exclusively on the relationship the researcher builds with the participant (Marshall & Rossman, 1995, p.65). Establishing the relationship as reciprocal and intersubjective, provides a context for a caring partnership in research (Van Den Bergh, 1996). My intent was to receive an education about FAS through the participants disclosures and expertise. In turn, I was able to share with the participants, how I as a social worker, really knew very little about how the syndrome played out in their lives as adults and that I earnestly wanted to hear their perspective. I discussed some of my own personal experience and the reasons behind my desire to research this topic. This mutual type of discourse allowed the establishment of rapport which in turn enabled me to learn both about the participants and myself, particularly with the two participants which I chose to interview a second time. I was able to come away with a greater understanding about the dynamics of working with individuals who have FAS/E, as well as the nature of the disability in adulthood.

In order to achieve more of an in-depth understanding of the experience of FAS in adulthood, I sought to re-interview two of the participants in order to clarify certain points in their stories, as well as to seek their opinions on some of the findings which were emerging. The second interviews provided an opportunity for further clarification and the presentation of more in-depth discussion thus enhancing the credibility of this study.

I personally transcribed three out of the five initial interviews, as well as the second interviews. A copy of the transcript was given back to all of the participants except for two who indicated that they didn't need to have them. Due to the participants expressed reading difficulties, I did not expect that the transcripts would generate further feedback, however, it was important that the participants have a copy of their story.

Data Analysis

Marshall and Rossman (1995, p.111) state that the practice of data analysis is a process of “bringing order, structure, and meaning to the mass of collected data while searching for general statements about relationships among categories of data”. In my research project, the nature of the research data included transcripts from audio-taped interviews, and a journal in which I kept field notes. Marshall and Rossman (1995, p.146) state that keeping “thorough notes and a journal or log that records each design decision and the rationale behind it, allows others to inspect the researcher’s procedures, protocols and decisions”. This assists the organization of data while “making them easily retrievable and manipulable” (Marshall and Rossman, 1995, p.111). Maintaining this type of organization of the data throughout the analysis, establishes further credibility of the study.

Data analysis began with the transcribing of the first interview. The transcription process emphasizes the importance of capturing the participants’ own words while giving the researcher “authority as editor, translator and interpreter of those words” (Sandelowski, 1993, p.314). I chose to transcribe the first interview myself and I did this before conducting interviews with the other participants. Personally transcribing the data verbatim, allowed

me to become fully immersed into the data and it also generated discoveries which caused me to conduct the second interview in a slightly different manner. For example, the preliminary analysis of the first interview lead me to modify my initial question, thus enhancing the richness of the study. I also decided to transcribe two other interviews myself, a process which permitted me to be more involved with the various nuances particular to those participants' responses. In order to remain involved with the transcription process of those interviews which were transcribed verbatim by a transcriber, I decided to play the taped interview out loud as I read the transcript. The second interviews which I transcribed myself, were not transcribed verbatim, due to time factors.

The process of data analysis was exactly that: a process which evolved, dependent on the steps I took. Becoming familiar with each transcript as a whole was my initial step. Turner (1993, p.178&179) states that the researcher must become familiar with the range and diversity of the data by means of a thorough overview of the data. This then leads to the next step, the process of abstraction and conceptualization, which enabled further insight into the essence of the experiences of the participants in my research. The meaning of the experiences of the participants were viewed with greater clarity as themes were uncovered within the body of the text. VanManen (1990) indicates that any lived experience allows the researcher to uncover certain themes which convey the essence of the experience being studied. VanManen (1990, p.92 & 93), discusses three approaches for isolating themes during the analysis of the data: a holistic approach which involves a focus on certain phrases or sentences which could adequately describe the essence of the text as a whole; a highlighting approach which involves selection of certain statements of phrases which captures the theme of the experience; and a line by line approach which views every single

sentence in order to determine what is being unveiled about the experience. Uncovering the themes and then placing them within a framework, allows for the meanings of the participants' experiences to emerge and develop clarity, thus broadening the understanding of the phenomenon being studied.

After the familiarization process, I felt quite anxious about missing key meanings, so in order to conceptualize the data, I found myself employing a line by line, almost word by word, detailed analysis. I took every idea represented in each line and formulated a code; a code being defined here as a label of the presented phenomenon (Miles & Huberman, 1984). I would then place each code beside the corresponding sentence in the right-hand margin of the page. Upon completing nine pages of open coding, I reviewed my method and the codes and felt that it was too rigid and constraining. This line by line approach did not really leave me with any sense of the participant as a whole and only served to frustrate me. I still did not feel that what was being generated would adequately represent meaning of the participant's experience. I had no sense of analytic direction.

Re-evaluating my position, after further re-readings of the text as a whole, I approached the data from a more holistic approach, where I would reflect and note certain phrases which gave me a sense of the facts within the text pertaining to the phenomenon of FAS/E. Re-readings of the transcripts illuminated important sentence clusters which stood out as reflections of the participants lived experiences of FAS, and, which generated further interest and discovery into their experiences for myself. These clusters would represent themes, which I sometimes summarized in my own language, but most often utilized the language of the participants, as an effort to stay true to the voices of the participants. All

this took place within a strategy of returning to the overall meaning of the text in light of the parts which were illuminated, and making comparisons to what was emerging within the other transcripts. VanManen (1990, p.32) describes a true reflection on lived experience as a “thoughtful, reflective grasping of what it is that renders this or that particular experience it’s special significance.” Essentially, my analysis of the data became a layered, circular process, a going back and forth operation from a general view of the data in order to grasp it’s overall representation of the participants’ lived experience, to re-readings involving a highlighting approach which allowed me to select sentences and phrases revealing the special significance of the particular experience. Constantly comparing themes, and then reflecting on the findings with my advisor, harnessed several perspectives of the data. All the significant statements were highlighted with a coloured marker in the transcript. I discovered rich sentence clusters which informed my research. Key phrases were highlighted, often marked by using the words of the participants in order to capture the conceptual meaning. Stories and quotes which were reflected in the highlighted categories were coded. The codes were representative of the participant’s experience and along with running memos, were documented within the body of each transcript. By comparing each code to the other codes which were emerging, I noted certain themes which I felt captured the meaning of the experience, and these were highlighted by the same name. This method was employed for each individual interview.

Categorizing these key meanings constituted my next step. With the accumulation of data I then proceeded to photocopy the transcripts, cut the coded quotes and then group the quotes according to the similarity of meaning and commonalities between and amongst them. This was done in order to establish a working framework. The quotes were pinned to a very large

corrugated board which allowed for an overall visual contact of organization, keeping me in touch with the participants as individuals but also part of a whole. Eventually the information became more organized, with larger dimensions of the participants experiences broken down into properties of the larger category. This visual way of managing the data proved to be extremely useful as it allowed me to locate information used during ongoing comparisons, and, when it came time, to illustrate my findings with specific quotes.

I want to emphasize that the procedure of data analysis and the process of conceptualizing the data was not an easy task for me. I experienced many periods of frustration. In retrospect I sense that my frustrations in developing a conceptual framework was inclusive of the frustrations the participants often felt in terms of being understood by others. The wrestling with the data was a process of constant comparisons and continual revisions which involved checking, questioning, re-evaluating, exploring and reflecting upon the data. Finally the experience of FAS/E in adults was satisfactorily illuminated through three specific dimensions: Impact on Cognitive Development, What's the Matter with Me? and, What Helps? These three dimensions of FAS/E in adults contain subcategories which comprised my framework for understanding the lived experiences of the participants in my study. The final results enabled the extracted information to describe and maintain the context of the participants' responses while continuing the connection between parts of the data to the whole in which they were embedded (Sandelowski, 1995, p.374).

Criteria of Soundness

The integral components to the process of research involves the craftsmanship and

credibility of the researcher who seeks to establish the validity of the study (Kvale, 1995, p.241). While striving to illuminate the perspectives of the participants in the research as well as acknowledging preconceptions and assumptions embedded in the researcher, there are standards of establishing reliability and validity in the project via certain strategies. This is crucial to the trustworthiness of the research. To punctuate the importance of this, I will now present the criteria which, as part of my research design, allowed for a sound and credible project. The indepth applications of these criteria have been demonstrated previously as I outlined my methodology, but are reinforced in the following points:

1. Documenting procedure, protocols and decisions (Marshall & Rossman, 1989) through the use codes and memos within the body of each transcript, and within a reflexive journal, allows for others to inspect the process, thus enhancing the confirmability of this project. The analytic categories and interpretations of the participants experiences, were checked and re-checked via the inclusion of the participants, as well as my advisor. The time spent with each participant, particularly with those I interviewed a second time, allowed for greater clarification and enhanced interpretation. There were also debriefing processes which occurred with other persons in the field experienced with FAS and alcohol related effects. These strategies increased the credibility of this study.
2. The aim of this study was not to generalize the findings but to develop the data into a framework which provided a contextual understanding of FAS in adulthood. The participants perspectives via their expressive language establishes the validity of this study. Hence, the contextualization of their experiences demonstrate the meaning of FAS in adulthood, increasing the visibility and understanding of this little known

phenomenon. Marshall & Rossman (1989, p.145) indicate that “an in-depth description showing the complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid”.

3. The thick description of the design of my study demonstrates how the data collection and analysis proceeded, and, is inclusive of the various difficulties which I encountered. The parameters as described lend to the transferability of the study, which in essence determines how applicable these findings are to another population group similar to the first.

The criteria for soundness which I have outlined, encapsulates the decisions throughout the design of my research, therefore ensuring my methods as trustworthy and confidence in my findings.

CHAPTER THREE: MAKING SENSE OF THE EXPERIENCE

Introduction

The issues which I have chosen to explore in this chapter have arisen in the context of listening to the voices of five adults who have Fetal Alcohol Syndrome or Effects. The experiences of the participants who chose to take part in this study, reflects their perseverance, and it is the aim of this chapter to acknowledge, respect and validate the voices of the participants as they shared with me their past histories and current situations in order to assist me to understand fetal alcohol syndrome beyond it's diagnosis. Upon analysis of the data, I discovered that the portrait of a fetal alcohol affected adult individual was more complex than what I originally expected. The profile that was emerging included a wide range of considerations. I began to realize that fetal alcohol syndrome and alcohol related effects spans a whole spectrum of difficulties and competencies which are not necessarily consistent or simplistic in presentation.

The Participants

The five participants who assisted me with this study are represented by a pseudonym. The pseudonyms allow anonymity and protection for the participants. They are Janice, Roberta, Brenda, Ted and Lisa. All five of the participants are adopted. A brief overview in order to become better acquainted with them will now be presented.

Janice presented as very energetic with a warm personality. She is 24 years old, living at home with her adoptive parents and maintains some employment. Her birth mother was a

heavy drinker and Janice was born while her mother was in detox. Janice received her diagnosis of Fetal Alcohol Syndrome when she was age 20.

Roberta presented as confident and verbally articulate. She is 20 years old, living at home with adoptive parents who are extremely educated in the field of FAS. Roberta works part time. Roberta has Fetal Alcohol Syndrome and received the diagnosis during early childhood. Roberta has been involved as a speaker in several FAS conferences.

Brenda presented as friendly and very open. She is age 21, living at home with adoptive parents. She was diagnosed with Fetal Alcohol Syndrome when she was almost 17 years old.

Brenda gave this description of her birth "they said that when I was born, it smelled like a brewery in there."

Ted was the only male in my study. He presented as gentle and soft-spoken. He is 20 years old and was diagnosed with Fetal Alcohol Effects when he was 14 years old. He is employed full time and lives at home with adoptive parents.

Lisa is age 26, adopted and diagnosed mentally handicapped, the result of Fetal Alcohol Syndrome. She received the diagnosis during her teens. Lisa is part of a large, longitudinal study on FAS and was very eager to contribute to my research project. Lisa lives away from her parents in a private care situation where she is able to be semi-independent.

The above snapshots of the individuals in my study are but a brief introduction to their valuable stories which have enriched my understanding of Fetal Alcohol Syndrome. All were

eager to share their stories with me and were very patient with my questions as I struggled to understand the issue of FAS from their perspective and to represent their perspective accurately. The next sections of this chapter unfold some of their lived experiences, providing a context from which the issue of Fetal Alcohol Syndrome in adulthood gains greater visibility and dimension

Findings

The most salient and consistent points that were brought up by the participants, were finally represented through three main categories. However, these categories present a simplistic picture of themes which are more interrelated than what they seem. **Impact on Cognitive Development**, forms the basis of understanding the cognitive struggles of the participants. This category is comprised of three main properties; **Memory and Comprehension**, **Hyperactivity and Decision Making**. **What's the Matter with Me?** is the second category which emerged as the participants discussed thoughts about their sense of self. The third category, **What Helps?** represents the elements of support for the participants and encompasses three properties; **The Diagnosis, Different Ways of Learning**, and **External Support**. These categories along with their respective properties make up a framework which generates a clearer understanding of the nature of this disability.

In order to have a succinct picture of the findings, the following organizational chart draws a focus to the themes above. More often than not, the elements of the properties are the words of the participants themselves.

CATEGORY	PROPERTIES	ELEMENTS
1. Impact on Cognitive Development	Memory/Comprehension	Problems Understanding Frustrated Learning Affects your thinking Hard time remembering
	Decision Making	Trouble making decisions Bad choices Poor judgement Not knowing right from wrong
	Hyperactivity	Really hyperactive Impact on school/home Getting distracted Problems concentrating Medication Issues
<hr/>		
2. What's the Matter with Me?	Sense of self	Trying my hardest Sense of failure Low self-esteem Feeling stupid Hating the self Getting picked on
<hr/>		
3. What Helps	The Diagnosis	Positive relief Knowing Finding out more Cautions
	Different Ways of Learning	Active learning External Structure
	External Support	Family Other Relationships Community Supports

It requires only a very short stretch of the imagination to realize that virtually all that we are and do involves memory. More specifically, learning, development, and memory are inextricable linked.

Guy Lefrancois (1980)

Impact on Cognitive Development: The Challenges

Cognitive development is best described as the development of such things as knowing, perceiving, problem-solving and decision-making, awareness, and related intellectual activities (Lefrancois, 1980). In other words, the ability to process information, comprehend it and remember it. The ability to process information allows for appropriate interaction in relationship to the world's complexities. Fetal alcohol syndrome and alcohol related effects are medically documented as a neurological disability which interrupts the information processing mechanisms occurring in the brain. Generally when information processing deficits occur, impairment results in terms of the brain's ability to either record, store, and/or interpret information. In terms of fetal alcohol syndrome, impairment results to varying degrees in all three arenas. As a result, there are a variety of ongoing cognitive difficulties for the affected individual which can interfere with various aspects of daily living for the rest of that individual's life.

During the interviews with the participants and throughout the analysis process, I noticed that the stories of the participants reflected incidences which could be interpreted as events which likely occurred because of disruptions to their information processing ability. While there were inconsistencies in terms of how fetal alcohol syndrome impacted the cognitive abilities

of the participants and how the participants interpreted the impact, there were nonetheless certain consistencies which emerged, related to cognitive development. For most of the participants, some of their reflection focused on difficulties which usually occurred within the education system, and it was largely within this context that I could clearly see the impact of fetal alcohol syndrome. More often than not participants would spontaneously reflect upon the difficulties which occurred during their school years. The participant's stories revealed **memory and comprehension problems, hyperactivity**, and some talked about their tendency to make **poor decisions**. These issues all developed as thematic properties which set a foundation of understanding and gave me an appreciation of the challenges the participants encounter.

Disruption to Memory and Comprehension

Within the context of cognitive impairment, the disruption to memory is an important finding and consists of problems with **remembering** and **comprehension**. Repeatedly, the participants revealed and discussed their difficulties remembering information and/or understanding information presented to them. These themes are interrelated and woven so tightly within the participants' descriptions, that I felt it was necessary to keep these two themes linked. The participants demonstrated through their stories that memory and comprehension are two events of cognitive functioning which are exceedingly important and when disrupted, sorting out and relating to the complexities of the world can become frustrating, confusing and sometimes dangerous. One participant, Brenda, summed this up in the following statement: "*It (FAS) affects your thinking, your behaviour.*" Elaboration of this feature of FAS will now be presented through stories of the participants.

Four of the five participants involved in my study, gave various illustrations of hindrances to memory which they felt was the result of FAS/E. Ted acknowledged that "*I do have a hard time remembering things*" in terms of the general sense, but particularly keeping straight a series of tasks given to him by an employer:

The boss'll ask me to do this, this, this and this, and I might forget the smaller thing to do...and then he'll tell me again.

Ted's quote demonstrates problems with memory retention, but in the context of being given more than one instruction at a time. Brenda also has these similar difficulties with memory. Brenda stated that her memory did not interfere with simple tasks throughout the day at home, but that there are difficulties:

Usually I have an awesome memory. I can remember all the way back to when I was two years old. I can remember phone numbers from when I was five. I can remember the numbers/codes at work...but when it comes to a book, I cannot do it...(At work) if someone goes and tells me to do a couple of things I'll remember one and not the other.... My mom knows ...she tells me one thing to do....if she rambles a whole bunch of things for me to do, I won't remember them.

My understanding of Brenda's description of her memory is that long-term memory is not a problem, but other aspects of memory are. It seems that there is some confusion when directions involve more than one step. A series of information given at once does not work, either for Ted or Brenda. This aspect of FAS seems to hinder their ability to retain immediate information or instructions unless it is simply and clearly presented, one step at a time.

Difficulties with memory interfered with learning, according to Roberta, Janice and Brenda. These three participants illustrated problems with remembering, particularly related to understanding or retaining information from reading material, both during school years and currently. Their descriptions seemed to indicate that the problems which they had with memory created difficulties with literacy:

*I'm not a reader at all, I didn't learn how to read until I was twelve
Like if I read a novel, I'd read the first page and go on to the second
one, and I couldn't remember what happened in the first page....I'll
sit and read the whole front page, and then I'll turn and think ooh, this
is interesting...and I'll read that second page and go huh? and I have
to go back to the first page....If I'm at a bank and they tell me read this
before I sign it and stuff, I don't know what I'm reading. I sit there and
look at the page for however long it would take to read it but I don't read
it. (Brenda)*

*If I'm sitting there and I don't read it (a book) out loud, I'll forget...
I don't have the patience to sit down and read. (Janice)*

For Roberta, the following quote indicates courses in school became very difficult because of the required reading; she simply could not remember what she'd be reading and from that point comprehension was also affected:

*I could be reading something, but, at that time, it would just, it
wouldn't click in. I could sit there reading it, and then a couple of
minutes later somebody would ask me "what did you just read, tell
me what it was about", and it's like uhhh. Didn't really remember
it, and I didn't really understand it. (Roberta)*

Roberta's use of the phrase "*it wouldn't click in*" and the words "*remember*" and "*understand*" point out her cognitive struggle. Her quote reveals her attempts to grasp the meaning but she can't, so remembering the material is impossible. Memory and comprehension are unavoidably linked.

In addition to remembering written material or understanding it, Roberta and Brenda also found it difficult trying to remember what was said to them orally, and then transferring the information onto paper for future reference. Thus, tasks such as note taking became an immense chore:

I've never been able to take notes. It's like people tell me oh well, just write down what you think is important. Well what is going to be on the test is what's important, and I'm not gonna know....I wouldn't write anything down. (Roberta)

I don't know how to take notes. I do NOT know how to take notes, like I had a note-pad, and everything, and I'd be like pretending I'd be writing, and I'd be writing a note to my boyfriend, and stuff like that. (Brenda)

Brenda's account demonstrates that note writing in itself is not the problem as she was able to write a note to her boyfriend. My interpretation is that the problem appears to be with tracking the verbal message and remembering the information long enough to organize what is being heard so that it can be translated onto paper. Brenda illustrated this point further as she continued to talk about what happened during job training in hairdressing school:

They'd (teachers) be sitting there talking to me, and teaching me stuff

*and I'd be like, what did you just say, like what? I don't understand.
.....I'd lose it, I couldn't sit there and listen to them, I couldn't
understand what they were saying....to the point like, like I knew what
they were saying but it wasn't comprehending in my mind that it has to do
with something.(Brenda)*

This incident which Brenda recited revealed the difficulties she has processing information. Brenda expressed that she knew what the instructor was saying but she couldn't make connections "*it wasn't comprehending in my mind that it has to do with something*". She indicated that she knows what was being said, but that it didn't make sense. My understanding of this phenomenon was that for Brenda, comprehending the incoming information, remembering and organizing it, and sorting out the pertinent points was very difficult. Consequently, learning information and applying it is difficult.

During the analysis, as the participants talked about difficulties with memory, I noted various connections the participants would make to the issue of comprehension. I was aware that sometimes memory problems are generated by comprehension difficulties. This is because when we attempt to remember, we are generating memory on the basis of understanding. Comprehension has an effect on recall because memory goes beyond a retrieval system and relies on comprehension (Lefrancois, 1980). In my estimation, if an individual's memory and comprehension are affected, then it would be inevitable that the way that person interprets their world would be different. I asked Brenda during my second interview with her, to further help me clarify and understand this whole issue of comprehension, tracking, and memory from her perspective. She clarified my understanding by describing what goes on for her inside her head, during one-on-one conversations she has with people, or, if she is

listening to instructions or information etc.

"I can see them talking but I can't get it inside my head. Cause it's like, it doesn't mean anything...and I notice it too, so I try really hard to listen but I still can't...Even when you (Darlene) sit there and talk to me, I have to really, really listen...nothing is going on around me (to get her distracted)...I can see you talking but I just can't really understand...it's not that I can't understand the words that you're saying it's just that—my brain doesn't want to catch everything I guess. It's really hard to explain....especially long sentences...if they are short sentences, fine but if they start going into something, well, it's just weird...I know I'm doing it too!! I try harder to listen, it's almost like I'm staring into nothing...It's almost like Charlie Brown....you know the adult's can't, they don't let them speak English, they just yaakka (imitation of the sound) that's how it is...the adults they won't speak English, or they won't speak, but they'll make a noise and it's not making sense..it's making sense to them but it won't make sense to you...that's how it is!

Brenda's explanation really illuminated my understanding of her cognitive processing difficulties related to fetal alcohol syndrome. It seems to me that there are a combination of things which occur; words and phrases are heard but not understood, but then again some words and phrases are understood but simply not heard; parts of conversation go missing and essentially this creates a situation where the input which needs to be processed, just tends to get very jumbled. The Webster's dictionary description of comprehension is "to grasp mentally; understand, to include; take in; comprise". This is reflected particularly in Brenda's explanation of FAS. From my perspective, it's a combination of comprehension, memory, and tracking all being hindered for Brenda. She has only grasped parts of the incoming

information. Couple this with distractions, and the end result is that massive pieces of information do not get processed or recorded for her.

Roberta is another participant who also expressed how FAS impacts this aspect of cognitive process:

I just have more problems with, like understanding...understanding like the concepts of situations.(Roberta)

What is being said by the participants seems to indicate that they have difficulties with recording, storing and interpreting information, aspects of cognitive development which when hindered, creates many challenges to grasping the full meaning of a text, a verbal explanation or a situation. The implications of this are reflected in Brenda's words "*it won't make sense*".

If it is difficult to grasp the full meaning of a situation, frustration can occur and misunderstanding generated. Ted spoke to this in the context of school difficulties and there is a similar thread in Brenda's and Roberta's accounts. All expressed various difficulties "understanding" the full meaning of what is being expressed to them. Ted stated that he found school "*pretty tough because I didn't understand a lot...I was frustrated*". Given this, Ted asked for help frequently but even when he did ask for help with problematic concepts, he would often still not understand verbal explanations, thus even an attempt to rectify the situation would compound feelings of frustration:

When I had a problem and I couldn't fix it then I'd sort of get

get frustrated and uptight and I'd have to ask the teacher and then I wouldn't understand her.

It should be noted that the words "frustrated" or "frustrating" appeared numerous times throughout the stories of the participants. I discovered through the analysis of the data that these two words were usually scattered spontaneously throughout the participants' comments about various learning experiences. To me, the frequent use of these words by the participant's revealed their feelings in regard to processing, understanding (comprehension) and remembering information.

Decision Making

Participants demonstrated through their stories that memory and comprehension deficits created difficulties for them as they attempted to learn. In addition to this, the participants reflected upon FAS/E as creating difficulties for them when it came to making good decisions. Hence another significant category emerged during the analysis of the data.

Decision making is a theme which discusses various problems the participants had in evaluating sensible, healthy choices for themselves.

Brenda stated in a very honest way that the worst thing about living with FAS was the tendency for her to make decisions that were not good for her life:

I have trouble making decisions, if they're bad or they're right, and that's what has been the hardest throughout my life. I realize that it's right or wrong after I've done it, and then that's what makes it really bad....cause you can get in a lot of trouble and I've gotten into gotten into lots of trouble.....it's hard to say no to things.

Brenda's description reveals her difficulties in evaluating choices until after she has lived out the consequences. She gave me the following example:

One time, I forged a cheque (mom's) and got \$800, went out and spent it all in, like a weekend....rented a boat and everything, and didn't care, until, now I do. Like I feel really bad about it, but, like I was saying before, you don't care until after it happens, and you realize you did something that was actually wrong.

Importantly, when Brenda spoke of her tendency to make poor decisions and choices for herself, I could see that she really was not deliberately trying to get into trouble. Certainly throughout the interview with her I could hear the remorse in her voice about some of the difficulties she found herself in because of poor decisions she made. She stated several times how bad she felt looking back on some of the things she had done. It seemed that her lack of discernment and impulsivity would overtake her. Even with some external structure assisting her, (for example, the wisdom and protection of her parents) she would often find herself in situations that were very difficult; situations which I interpreted as occurring because she did not comprehend, or fully grasp cause and effect:

You just don't realize until afterwards....I used to do anything and everything, just, you know, for the hell of it, or just to have fun....but there'd be so much trouble....you think of having fun, you think you're going to have fun, and what's wrong with that and then you realize fun turns into trouble and trouble turns into danger...it's not like I was raised in an awful, awful family.....like my brother is the sweetest guy in the whole world, and there's me, and I sit there and I wonder how come I didn't turn out like him? And then, I think, it's because of the fetal alcohol syndrome.

My reading of Brenda's illustrations is that cognitive difficulties, particularly with comprehension hindered Brenda's ability to make good decisions or responses. She points out that she did not realize until after that she did something wrong. In her words previously stated in this chapter, fetal alcohol syndrome "*affects your thinking, your behaviour*" and therefore difficulty in relating behaviour with consequences can create some very serious problems. Immediate gratification overrides sensibility. She stated further that "*I don't even know how it works. ..If I get something in my mind I'll just do it and I won't think about the consequences until afterwards*".

When I asked Ted about what he felt I should know about how FAE impacts his life, Ted also spoke about being aware of having problems with making good decisions, but he termed this as having "*poor judgement*". Ted related this example:

I was having the 19 year old power struggles with my parents. They'd tell me what to do and I'd say I'm 19 whatever, so I left, went on my way, lived with a whole bunch of different friends. I didn't have a job, I quit going to College, I quit my hockey, I just went and lived with different people and then I finally found this guy I knew. I didn't know him that well although I thought I did. He was sort of another bad choice I was about to make. He lead me the wrong way....I had some money saved up and he said let's go take it out. It was quite a bit right, lots, and uh, I wasn't going to take it all out because the amount I was going to take out would have been enough for a few weeks. I didn't realize you know, I did deep down but I wasn't at the time thinking about it. Luckily my parent's friend....said "what are you doing?" He sat down and talked to me and I said, yeah, what AM I doing?

Ted refers to this negative peer relationship as "*another bad choice*" he was about to make.

My interpretation of the events Ted described is that difficulties with comprehension can disable skill development in the areas of social perception or judgement. Ted stated that he realized he was getting in trouble "*deep down*" yet he "*wasn't at the time thinking about it*". Ted couldn't really sequence the events to understand where his choices were leading him until an outside source stepped in and caused him to really contemplate his decisions. It was then that he was able to focus and re-adjust what he was about to do. Both Brenda and Ted presented accounts which they saw as areas of difficulty because of FAS/E impacting their ability to make good decisions. For me, this theme also generated further questions about how well cause and effect is understood when the individual is impacted by FAS/E.

Hyperactivity

Another dimension of fetal alcohol syndrome/effects which emerged through the data presented by the participants, was the issue of hyperactivity. Hyperactivity was selected as another important finding because it appeared to contribute and exaggerate problems when the participants were trying to learn. Hyperactivity has been widely written about and the difficulties which hyperactivity presents are certainly not minimal. The hyperactive individual is usually in constant motion, unfocused, distractible, talking loudly, excessively and out of turn. They may be repeatedly admonished for their inappropriate behaviour only to repeat it over and over.

Regulating and organizing behaviours, thoughts and emotions become difficult and impact many areas of the individual's life. During the interviews with the participants, several participants clearly named hyperactivity as having an impact on their life. One noteworthy

example about hyperactivity which Janice discussed, describes the difficulties and the desperation it can create in the classroom:

I never sat in my chair (at school). I used to always get up and look up and look at other kids work, and get sent to the office cause one cause one teacher did not know how to handle me... and I was even belted down to my chair so I couldn't get up anymore. (Janice)

When I asked Janice how this event impacted her, she used the word “*interesting*” and chuckled about the experience. However, when I reflected about this event, I could not help but think how difficult or even frightening this may have been for her. Her body was doing what it couldn't help doing and lack of knowledge about the disorder at the time created desperate or drastic intervention methods. There was a lack of control both for the teacher and for Janice as a child. Any assumption that Janice could control this behaviour would have been wrong. As an adult, the hyperactivity still creates some problems for Janice:

I'm always go, go, go, my body wants to keep going and then my mind wants to shut down, so what happens is I start hyper-ventilating. (Janice)

Roberta provides an interesting description about the impact of hyperactivity in her life, some of which seems parallel to some of Janice's experiences:

I drove them (family members) all crazy...I was really hyperactive. I was like to a point where I was constantly bouncing off the walls. I never slept....I was always on the go it was just, I could not sit still, for not even a minute. If somebody like paid me to do it, I just couldn't do it....I failed Grade 1 because of my hyperness. Because it's like,

the teacher would tell me to sit down, I just couldn't sit, so I'd be up and around...I'm not quite sure why I went through all those foster homes. I just imagined it was because I was really hyperactive....people just could not control me.(Roberta)

Roberta's reflection indicates her understanding that behaviours which are hyperactive are exhausting for people around her. Roberta's task became one of having to exert some control, and the following account reveals how she currently deals with hyperactivity. Her story provides information about what can help:

Even now there's still times where I get really hyper. But I know now, how to calm myself down. If I get out of control, it was like, before, I would have to have time-outs and I'd have to just sit down, and for about like ten minutes, just calm down. And then I could carry on to what I was doing before. If I start, and I know that I'm starting, then I can bring myself down. I change what I'm doing...I'll just bring the activity I'm doing to more of a lower one, to something that's a little calmer and it's not so, that I'm going to be to a point where I'm gonna be bouncing off the walls.

Brenda is another participant for whom hyperactivity created an impact, particularly while in school:

I'm really hyper, I'm really, really hyper, you can ask anybody....I couldn't even be in there (school) for like a whole day. I'd be sent home. By the end of the day I'd spent half of my time in my bedroom.

Brenda's quote parallels what Janice and Roberta indicated; that behaviours related to hyperactivity impacts not only the hyperactive individual, but also those in relationship with that individual, particularly family members and school personnel. The impact appears to be

largely negative. However, I discussed with Brenda if hyperactivity continues to play a role in her life, she stated that it had toned down a bit, but used the words "*happy*" and "*bubbly*" to describe this aspect of herself. This reflects a way of reframing aspects of hyperactivity in a more positive way:

I'm still always happy now...sometimes I get really bummed out.....and then other days, I'll just be like, off the ceiling, I'll be like.....dancing and singing...all my friends know that, like if I'm bummed out, they totally think something's wrong. Like, "what's wrong"? I'm like, "nothing". "Something's wrong". "No , nothing's wrong". They're like, "well you're not your normal self....you're not bubbly".

Connected to the issue of hyperactivity, are other related problems such as distraction and concentration difficulties. Brenda stated that "*school was not for me. I didn't like school, um, it was really hard for me to concentrate*". Brenda elaborated that during conversations she'll get distracted by something in the room and while she would be trying hard to pay attention, what occurs is this: "*sometimes my mind will go somewhere else...I'll see a picture or something, I'll think, oh I remember that, andI totally missed it all.*"

Distraction was also a problem for Roberta. However, when she found herself in a smaller classroom the work became more manageable because she was able to concentrate better "*It was a really small class and everything, so that was cool, because then there wasn't so much distraction*".

Distraction and concentration were such difficulties for Teresa, we had to change our positioning during the interview (when we were talking about concentration) because she was facing a window and got distracted by what was going on outside the room. She knew she

was getting distracted and brought it to my attention although I could see for myself that I needed to restructure our position:

(In school) sometimes it would be uh, sometimes, really hard to.... to be able to concentrate on my work. There's somebody, someone out there walking by that's why you can see I'm not concentrating cause its, there's a big window there and if, someone is walking by, you can tell I'm easily distracted.

Sometimes during the treatment/management plans for the cognitive and related behavioural difficulties brought about by the impact of fetal alcohol syndrome, medication is utilized. Tanner-Halverson (1995) states that "when medication works, the results can be phenomenal". In my research, the issue of medication surfaced as a potentially important issue, worth noting. For Brenda, Ritalin became the preferred mode of treatment for her hyperactivity, distractibility, and poor concentration. It was a treatment which worked, bringing relief to Brenda's hyperactive behaviour and subsequent concentration difficulties. Even though Brenda acknowledged the effectiveness of the medication, she chose to go off the medication when she reached adolescence:

They put me on Ritalin, like they put any other hyper kid on Ritalin to concentrate which I do admit it did help for a long time, but then it was boring me, like I didn't want to be boring, I wanted it to be fun, and so I went off it. (Brenda)

Brenda previously discussed the hyperactive aspects of her nature which were described as "bubbly and happy". While Brenda had an adequate understanding that Ritalin helped, she saw it as interfering with these parts of herself which she liked; essentially I think that she

could not see herself as being fun or having fun while on it. The downside of this is that Brenda acknowledged that after she went off the Ritalin, at about age 15, she started getting into a lot of trouble and making bad decisions. Alcohol consumption became severe, and she found herself involved in some very unsafe activity... *"so I went off it, and I was about fifteen, and that's when I started doing bad things"*. Brenda went back on the Ritalin last year because when she was working she found it difficult to concentrate and she wanted to *"stay more alert"*. Unfortunately however, while the Ritalin still produced positive effects for Brenda, now in adulthood the drug contributed to Brenda feeling physically sick:

I could sort of see it helping, but it just, it make me sick....I got headaches all the time and stuff like that.....it calmed me down it made me more awake, that's about it...the only reason I went on it was 'cause of work.(Brenda)

Unable to tolerate the side-effects, Brenda went off the stimulant medication. Likewise, Janice expressed difficulties with medication. During my first interview with Janice, she stated that living with FAS *"has been a very rocky road...being on medication is really helping"*. However during my second interview with Janice a couple of months later, Janice told me that she abandoned the medication regime because she did not feel physically well while on it. I believe that Brenda and Janice's examples point out that while medication was not be the panacea that it had been hoped to be, it did give some relief. The positive effects are however unresolved for these two particular participants. Their accounts of both the negative and positive effects of medication points to the necessity of further research in this area.

What's the Matter with Me?

Patterns of getting into trouble because the individual is impulsive or hyperactive, and, doing things without fully comprehending social cues or cause and effect, often lead to frequent negative outcomes which were damaging to the individual's sense of security, competency and self-worth. Inability to comprehend and remember incoming information also undermined feelings of competency. While the participants had varied perceptions of their cognitive disabilities, it became clear to me that the tendency to individualize or personalize the disorder was not uncommon. I particularly noticed this as the participants discussed their struggles within the context of the school system. Their lives at school were wrought with difficulties, many of which impacted their self-esteem. Another category of significance occurred: **What's the Matter with Me?**

When I asked Janice about what it's been like living with FAS she stated emphatically that *"it's been a really, really, rough life"* and spontaneously began to discuss school and the varying degrees of difficulties she had there. Her difficulties included both the academic and the social aspects of school life. Janice stated that her school years were the most difficult of her life as her self-esteem was at an all time low *"I just, I hated myself, like I just ABSOLUTELY just hated myself"*. The following quote demonstrates some of the social difficulties which she experienced.

I used to always get picked on and called names. High-school years was worst than anything else...I was the underdog, like when I got there kids that knew me from elementary school would always say stuff and always call me names and, and pick

on me and I'd use to always get in fights and suspensions...like some of the name calling was sick, just sick, absolutely sick. (Janice)

For Janice, life consisted of constantly getting into trouble during both elementary and high school. She was misunderstood by peers and scapegoated. She had a sense of being different from the pack as evident in her choice of the word "*underdog*". She also stated that:

I'd have people comin in and spreading rumours around and I I didn't even know them and they'd say stuff.....everybody knew me and picked on me. (Janice)

As I probed Janice about what she thought the reasons were for her peer problems, she was unable to explain what it was about her that resulted in such hostility from others:

"I have no idea...I don't know, it was just really weird, they used to always pick, just for something to do..I was kind of a loner....I didn't really get along with very many people. (Janice)

I sensed that her inability to understand the behaviours of her peers was possibly connected to cognitive problems in terms of difficulties in perceiving social cues etc. During the second interview with Janice I attempted to clarify this. Janice explained that she saw herself as getting into trouble with others because of difficulties "*handling situations maturely...acting my age...saying stuff or doing stuff, I guess immaturely*". She confirmed that this was about being inappropriate at the wrong time. Lisa also discussed difficulties being appropriate, describing it like this: "*it takes me a lot longer to know how to act around other people*". These statements are important and worth noting. My

understanding is that both Lisa and Janice are referring to problems which occur for them in the realm of social perception. Their statements are important because if social cues are not perceived accurately or comprehended by someone who has FAS/E, their responses can be unknowingly inappropriate. The resulting impact for Janice was serious because she ended up hating herself. Currently she describes life as an "*on-going battle*".

Roberta made it clear to me that frustrations with herself often occurred during school as well. Learning difficulties made academic work difficult. Enjoyment of coursework and pleasure in reading was basically non-existent because reading and comprehending the material was such a difficult task. Roberta was able to "*ace electives*", courses which were more hands on such as sewing, foods and woodwork. This however was not a significant enough contribution to positive feelings of self worth. While Roberta acknowledged to me that the electives assisted somewhat in boosting her self esteem, failing at the required courses created a lot of frustration and dimmed the other successes.

It would get really frustrating, because I'd be trying my hardest and everything, but no matter what, it was just, I would not pass (science and socials)...I remember one test...this one time and the teacher, she put a happy face as a 'good try' and everything I was just,.....the happy face,,well, it was nice of her to do, but I still knew that I failed it and so, it was just kinda, well what's the point?! I always felt like I was just failing at all the subjects, the really main subjects.

This quote is important because it clearly reflects the inner struggle that Roberta felt at the time and is a demonstration of the feelings of helplessness which can easily occur when

learning difficulties inherent within fetal alcohol syndrome present themselves. For Roberta, problems in the area of memory and comprehension seemed to contribute to cycles of failure and frustration impacting her sense of competency. Roberta expressed this really well in the following statement which reflects the tendency to individualize the disorder:

I always thought....well, what's the point? My self-esteem was like, really low. I actually did at that time think I was stupid....it would get frustrating. Because I just could not figure out why I can't do it. I wanted to do it, so it was just like, I want to be able to do this, but I just can't, because it's just too hard.

Roberta demonstrates through her account that information processing is a strenuous task, particularly for those affected by fetal alcohol syndrome/effects. For those who have an alcohol-related birth defect, the strain which occurs as they attempt to sort out their world is compounded, creating a stress which erodes confidence they may have in their sense of self. The motivation to do the work was there. This was certainly not about Roberta being stupid. Simply, Roberta's cognitive limitations created confusion when learning new information.

In response to my question "How do you think FAS has impacted your self-esteem?" Brenda replied:

Sometimes I feel real dumb—and sometimes I feel real smart. The fact that the school system said I wouldn't read for the rest of my life...I didn't learn to read when I was supposed to but I did learn when I was twelve...so overcoming that was awesome.(Brenda)

Brenda further stated in response to employment situations that:

I feel really stupid if I can't remember it (a task) and I have to go back and ask...people in jobs and stuff, they don't understand...and I don't tell them because I don't want them to think that they've hired an idiot.(Brenda)

The constant bombardment of not being able to 'get it', or being slower to pick up on concepts, or not being able to remember things at all, and, because of this, possibly being seen as different by peers and misunderstood by teachers and employers, inevitably affected how the participants in my research viewed themselves. Hence, individualizing the disorder was not uncommon. Roberta also discussed how others who do not understand the disability of fetal alcohol syndrome can sometimes respond, thus compounding stress already felt:

*It was hard during the school years...from about Grade 7 to Grade 10 it was really difficult...in Grade 8 they were saying oh, if she'd try just a little harder, then she would pass, you know, she's just being lazy.
(Roberta)*

Roberta's reflection of this memory reveals the invisible nature of fetal alcohol syndrome and how the person who is affected with it can be easily misunderstood. To others in relationship to her, Roberta appeared to understand, while all the while she really couldn't. During Janice's school years, no-one knew she had FAS and consequently the education system didn't really know how to handle her "*I'd get sent to the office cause the teacher didn't know how to handle me.*"

Currently Roberta sees herself as more secure as an adult, and appears more comfortable with FAS in that she does not like to focus on FAS as a disability. She is outspoken about this and says the following:

The majority of this stuffit's taught me....a lot of accepting the fact that I have it and that it's not like, really, a big deal...I tend to find that, that some people, when they do know (that she has FAS) they're just like, oh well you poor person, oh, and then they start treating you like, as if you're like, sometimes it tends to make you feel as if you are actually stupid, you're below everyone else...I don't need that. (Roberta)

My understanding of Roberta's remarks is that she clearly does not want to be seen as different from others. Inherent in this is the need to have FAS less pathologized. However, her statement also reveals some feelings of conflict, as it contains somewhat of a contradiction when she says that (FAS) is "*not like, really, a big deal*" when throughout our discussion she referred to many incidences in her life which pointed to a variety of difficulties FAS has created for her life. My sense of this, is that there appears to be a tension between her desire to present her authentic self and the receptivity of that self by others in relationship to her. Roberta did not want to be seen as "different" because of the FAS. She states:

I just think that people should be more open minded and not treat those who do have it (FAS) with sympathy.....just treat them more as if they are just a regular person.

In some ways however, this presents a bind, because being affected by FAS creates certain inevitable difficulties, which the participants themselves clearly expressed. There is a tension then between wanting people to accurately understand how FAS/E plays out in their lives, and wanting to be experienced by others as competent.

Brenda expressed feelings of frustration, incompetency and a lack of self-confidence as she

discussed her future aspirations.

I want to do things with kids, I love kids....I've always wanted to work with kids, like I wanted to work in a day care, but then I didn't go through...see the problem is, that I don't want to go to school again cause I know it'll be so hard and I will not be able to....if my friend just left (college), she has troubles herself, and if she has troubles then I know that I will probably have bad troubles....Generally you're supposed to have confidence in yourself but if you already know that it's gonna be hard, then there's no purpose in even trying.(Brenda)

Brenda realized that she needed some training in order to secure a good job, particularly one that she would like, but felt frustrated because the task of learning did not come easily.

Because of this she felt hopeless about returning to school for further education/training and couldn't really see it as a viable option. With feelings as powerful as Brenda's, it is difficult to generate the motivation to persevere beyond where she currently finds herself *"like for schooling and stuff, I sit down and think of ways that could help me, but I can't"*.

Brenda's cognitive difficulties from fetal alcohol syndrome virtually paralyze her from moving forward and feeling confident about her abilities.

The participants discussed their various difficulties with memory, comprehension and the impact their learning difficulties had on their self-esteem, I was struck with how much energy they seemed to spend trying to understand the input from a complicated world. Even though this was not necessarily verbalized directly, sometimes the phrases "not motivated" or "what's the point" would come up as descriptions of themselves or situations. The implications here are that the deficiencies the participants encounter in themselves, make

maneuvering their way through the world tremendously challenging. The difficulties appear to be individualized in a way that is self-pejorative.

Janice talked about difficulties with *"taking responsibility. Like it's hard to take certain responsibilities...I just can't get motivated"*. Roberta was described as *"lazy"* by a teacher. Somehow I didn't necessarily see the participants as not motivated or lazy. I think perhaps they needed to spend so much more energy than others to give to tasks which are complicated because of fetal alcohol syndrome's impact on cognitive development, that they became continually exhausted and tended to "give up". This is evident through phrases used by a couple of the participants in their stories, such as *"there's no purpose in even trying"* or, *"what's the point"* in regard to events which required cognitive effort. To me, this points to the futility of "trying harder". Rather, it points to the necessity of "trying differently". In a world which demands high levels of literacy and where there is an expectation to sort out language, meaning and responsibilities in precise and independent ways, the fetal alcohol affected adult can easily become marginalized and overwhelmed by a system which is not designed for their slower cognitive pace. Motivation or laziness can be incorrectly perceived as the issue. These misperceptions can easily impact self-esteem.

The childhood/adolescent years of the participants, particularly reflected enormous struggles and strains. Hindered by a disability which interrupts aspects of the brain's information processing ability, the participants' accounts poignantly demonstrated questions they had about their sense of adequacy. Until the problems were named outside of the self, that is to say the participant's difficulties attributed to the disorder, the participants were vulnerable to

blaming the self, saying "what's the matter with me" especially when others in relationship to them would say "what's the matter with you". Consequently struggles with feelings of competency are on going for most of the participants and a desire to be understood apart from having FAS and despite of FAS.

Despite these struggles, there was also a sense that most of the participants seemed to feel more in control and less overwhelmed by the FAS in their adult lives. Ted, one of the participants explains his current perspective:

I feel like I'm doing a lot better with it, dealing with it a lot better and learning more. It doesn't bother me as much as it did when I was 16 or so....it can't be fixed so I have to do the best I can.
(Ted).

I sensed a more positive outlook from most of the participants as they discussed their adult lives. I believe that this possibly reflected the situations they were currently in. During the time I conducted the interviews, the participants were finished with the education system but continued to live in situations that were greatly supported. This raised questions for me in terms of the education system and the stress it creates for FAS/E individuals, but it also reflected the necessity to explore the dimensions of support in their adult lives.

What Helps: Identifying the Elements of Support

The participants presented stories which identified sources of help and ways to help.

The third theme which emerged during the analysis was, **What Helps**, and represents the

elements of support or help as identified by the participants. **The Diagnosis, Different Ways of Learning, and External Support** emerged as properties of the category **What Helps**.

These properties and their elements will now be presented and discussed.

The Diagnosis

Obtaining a diagnosis of FAS, was for all of the participants and their families, a beginning of their quest for knowledge to receive answers for what was wrong. Generally speaking, the significance of a diagnosis is that it allows for misconceptions about the affected individual to be eliminated and gives the problems which the individual is experiencing, context and meaning. The adoptive parents of all the participants in my research, sought out assistance for themselves so that they could understand and manage the behaviours of their children in a better way. For all the participants in my study, diagnosis came about through their parents' concern about behaviours which were interfering with many aspects of day to day life. Problems were occurring in school, with peers, health, or with employment. Diagnosis was sought on behalf of the participants; it was not their idea to seek a diagnosis. Janice recalled the following:

My parents thought we have to do something...I guess they got a hold of Dr. _____I had a meeting with her and talked and told her my mom was drinking when she had me...So Dr. _____ did all this stuff and I had all the symptoms, the shortness and the eyes, and the nose and my fingers....and diagnosed it, and then, my mom and dad were like how do we find out more about this? (Janice)

Brenda recalled that she was going to Children's Hospital and getting tested for other things

because her family knew that something was wrong they just didn't know what. Then, with the help of literature, understanding began to illuminate the family:

My mom thought about it (FAS) cause she read a lot about it. I think she was reading an article or something about fetal alcohol syndrome...and my mom said "that sounds like Brenda, sounds exactly like Brenda.

Roberta was extremely hyperactive, and in her case, she was fortunate to have had the diagnosis early. She was the only participant who received a diagnosis before adolescence.

I was really young, 'cause it's like, ever since I was adopted I've always known, because they've always let me know that, well the reason why...you're having problems is because your mother drank and everything.

While the FAS diagnosis was initiated by parents of the participants in order to put a name to the difficulties their child was experiencing, there were also benefits for the fetal alcohol affected individual. This is because the diagnosis gave context and meaning for problems which were not understood and as a result, personalized:

*Now that I am diagnosed I know what causes a lot, a lot of my stuff ...it's really good that now that I am, that I've been diagnosed, I totally understand why I was the person I was when I was younger. (Janice)
I understand about FAS/E a lot more, um, I don't use it as an excuse anymore. I just learn to cope around the problems (Ted)*

I think that it is important to have the diagnosis...I know now that FAS effects your thinking, your behaviour. (Brenda)

When I was really young, I was adopted. I was always sick. Nobody knew what the hell was wrong with me...until the diagnosis. (Lisa)

One of the most frequent ideas expressed by the participants was that diagnosis was important and allowed for a greater understanding of the self, usually because the diagnosis finally gave an explanation for what constituted the driving force behind certain behaviours which were considered problematic for themselves and others in relationship to them. I received the impression that there was a sense of relief for the individual and for the family:

We finally knew what was wrong. (Brenda)

Now I know what my mom and dad go through. My mom and dad said its too bad we didn't have you diagnosed earlier because we could have said to the teacher, you know, this is why she's always going....if I could go back to school now, if I could have been younger and they would have known, because now they're staring to know, they didn't know why I was hyper and why I was having problems and stuff and it was just hell! (Janice)

For Janice there was a wish to have known earlier about the diagnosis. Similarly Ted expressed the same wish. Throughout their lives these participants struggled with various behaviours they could not understand or manage very well. When the diagnosis occurred, problematic behaviours began to make sense and there was reflection about knowing about the disability earlier in life. Ted explains it like this:

I wish I knew about it before. That's for sure. I think that's cause so I could start coping earlier with it and thinking about it a little more. You know, so I could do better. (Ted)

Once the diagnosis was made, it allowed some of the participants an opportunity to learn more about the disability, thus contributing to a greater understanding of themselves. For Ted, the diagnosis prompted curiosity about the syndrome and what it meant for him:

Before the diagnosis, I didn't know anything about this at all...I wanted to learn more about it, and how I could deal with it.(Ted)

It appeared from the responses of some of the participants that one of the important functions that the diagnosis served, was providing an explanation outside of themselves about behaviours which were difficult for them to control. Diagnosis put a name to the difficulties the participants were experiencing and expanded their understanding of self.

While the prevailing message from the participants seemed to be that diagnosis is important and plays an important role in developing a greater understanding of the self, there were also messages that diagnosis can have a negative impact as well. This then serves as a caution regarding how the diagnosis is presented, because for some of the participants the diagnosis also had an ability to stigmatize and to be pejorative. Traditional models of diagnosis presents a diagnostic process which transfers power to define an individual into the hands of helping professionals. It focuses on weakness and not strength, the negative and not the positive. Roberta was one participant who had some very strong feelings about this. She discussed that it irritates her when so much of the information is negative:

It really irritates me because those who read about it, those that are doctors and they think, oh well, well they don't have any hope, there is nothing. Like, they're reading all about the negative, and then it's like,

then it's like, it's just....it always irritated me, because it's like, well what about the positive.....it makes it sometimes sound like as if I've got like some kind of disease or something. It's not a disease or anything, it's just a disability.

Roberta's quote indicates her desire that professionals focus on the strengths and successes of individual's who have FAS. Often the bombardment of the negative overshadows the positive.

Roberta shows strong feelings in other statements which reflect that professional attitude in response to the diagnosis of FAS/E can create a negative impact:

I've had doctors when I was diagnosed, saying I wasn't gonna make it this far. I wasn't gonna be able to read, I wasn't gonna have a job, I would never be able to live on my own...just because I have this, does not mean that I will not succeed.....doctors should never say how the child's life is gonna be. They should not be able to say oh well, they're never gonna make it...I just think that doctors and professionals should not be able to sit there and say how the person is going to grow up.

In essence Roberta is saying don't say that there is no hope. Her message to professionals is that it's more profitable to discuss what can be done instead of what can't be done. As well, Roberta cautions against pre-conceived ideas regarding the potential of FAS/E individuals:

They (professionals) can't predict...the person could turn totally opposite and become very successful.

Brenda also expressed that there is a tendency for limitations to be placed on individuals who have FAS/E. While there are significant challenges, there are also abilities which can be strengthened. Brenda states:

I don't think it (FAS) gives me an excuse to do things. I never use the excuse that I have fetal alcohol syndrome, so I can't do it. People think that if you have fetal alcohol syndrome you can't do this, or you can't do that.(Brenda)

Both Brenda and Roberta indicate through their illustrations that a diagnostic label can distort expectations. An emphasis on limitations occurs, rather than just simple relief from expectations which are unrealistic for a person who has fetal alcohol syndrome. This is opposite to what a diagnosis intends to do. The nature of FAS and alcohol related effects has inconsistencies from individual to individual, and so each person needs to be considered on their own merit.

The following quote highlights the ease into which a diagnosed individual can feel the pejorative effects of a diagnostic label. The stigma effects from the diagnosis appeared to be in the context of how one participant, Brenda, initially felt upon hearing the diagnosis. I asked Brenda what thoughts went through her head when she received her diagnosis:

I didn't know what fetal alcohol syndrome meant when she told me. Like when I heard her talking to my mom that I had fetal alcohol syndrome, I thought I was retarded. I thought I had a disease....but when it comes down to it, if you just hear the words fetal alcohol syndrome, you think you have something serious. (Brenda)

It was clear from listening to Brenda and Roberta that diagnosis can also reflect negative, embedded assumptions on the part of the professional doing the diagnosing, and that this in itself can be stigmatizing and disempowering for the client. Brenda's mother took time to explain what the diagnosis meant:

She explained to me, like, "you're not retarded, you're just, you think you might be different than others...think about your temper, your drinking.....remember how you didn't learn to read until you were twelve"....she explained all the different things to me...that kind of sunk in, and then I figured, I'm not, retarded, nor a disease.

Diagnosis can also present some limitations which involve an inability for the diagnosis to move beyond the label to the development of a treatment response for the individual. Brenda expressed quite strongly that professionals needed to know more about how to actually help fetal alcohol affected adults beyond the diagnosis:

Professionals do need to know more about what the problems of the adults are and how they can help them...I don't know how to live with it (FAS) like really, like I've survived on, living with it, but I don't have enough knowledge on it, how it can, how I can help myself to make proper decisions, how to not drink, how to um, control my anger, stuff like that. That's something that I think people with fetal alcohol syndrome need, especially as an adult because as an adult you can get into more trouble than when you are a kid.

Brenda clearly outlines her need for further knowledge about her disability which can help her move beyond the diagnosis. Inherent in this, is the consideration that the deficits associated with FAS/E must be taken into account when trying to educate the individual about FAS/E.

For example, if the diagnosis is not explained exceptionally well, the diagnosed person will not have an accurate understanding of their disability. I found that my participants had difficulty describing an accurate working knowledge of FAS. During my interviews with the participants, I discovered that for many of them when asked direct questions about what they understood about fetal alcohol syndrome or effects, most of them answered the question by relating it to what they knew about the physical outcomes. They were able to describe what it was like to live with the disability, yet they had difficulties telling me in direct terms about the nature of fetal alcohol syndrome/effects beyond what they knew in terms of it's physical symptomology. Roberta states the following in answer to my question "what do you know about it (FAS)":

I know about, like, that hyperactivity, the um, the disabilities.... physical and facial disabilities, because I know that, like I know that, about the lines on the hands, um, I know about, like the elbows, because I have a tendency to dislocate mine...I know that a lot of um, are like, really, really, small and they tend to be underweight, that they're really like small and skinny, and they look a lot younger than they actually are....I know that like, it's hard to explain what I know. (Roberta).

Roberta's phrase "*it's hard to explain what I know*" reveals a wealth of information about how comprehension difficulties interferes with communicating about the disability and understanding how FAS/E functions. Prior to this question, Roberta was able to give a wealth of information about what it was like to live with FAS. However, when I requested more specific information, she had difficulties communicating.

In some cases, the information held by a couple of the participants was factually incorrect. During this phase of the analysis, curiosity emerged in my thoughts in regard to how knowledge about FAS/E was internalized and utilized by individuals who have FAS/E. During my interview with Lisa, a high functioning, mentally handicapped young adult with FAS, described fetal alcohol syndrome as a *“life threatening problem”* and felt that she was *“alive with the knowledge and stuff about FAS/E”*. In questioning what this knowledge was, I discovered that Lisa had lots of misunderstanding about how the disability actually works. Although Lisa stated accurately that her mental handicap was the direct result of FAS, later during the interview I asked Lisa about what she found most difficult about having FAS and in response to this she stated:

I sort of had lost most of, most of, this (FAS) it's like poison that has left my body, cause I've grown out of it so much, so later on it tends, to like, it tends to like leave. The alcohol is like a poison. I guess after a while it tends to drain out of my body and then, and then it'll do that a whole lot, so um, it's ...sometimes, like it, it effects me but not as much. (Lisa)

When I asked Lisa about how much impact she felt FAS had on her life she told me *“not a whole lot because I've lost it as I was growing up”*, yet Lisa recognized that her handicap was a direct result of FAS. From my perspective, these contradictions represent the participant's difficulties in conceptualizing and verbalizing what they know.

The tension within the participants' cognitive processes in terms of being able to reveal what it is like to live with the disability of FAS/E and how it impacts them, yet finding it difficult to

explain FAS, perhaps demonstrates the need for clarity in communication, particularly when dealing with explanations around the diagnosis.

Different Ways of Learning

The second property of **What helps** which demonstrates what assists the participants, was termed **Different Ways of Learning**. **Different ways of learning** was broken down into two elements, **Active Learning** and **External Structure**.

Active Learning and External Structure

As previously discussed, the participants identified difficulties with memory, comprehension, and learning. They also talked about difficulties with decision making, perceiving others incorrectly and others perceiving them pejoratively. As the participants recounted their stories it became evident that many of them were able to adopt survival strategies or coping mechanisms in order to compensate for difficulties. For example, it appeared that fetal alcohol affected individuals in my study required revised ways of learning in order to reduce their stressors. Ted spoke to this and provided a good example of how he manages:

I realize I have this (FAE) and , it takes me, like...different ways to learn things than other people do. I've learned to do it right away, do things, right that minute....and I use a book to write things down, you know, to remember. (Ted)

Likewise Janice, who described herself as "*slower to catching on to things*", clarified the best ways she remembered things:

If they (people at work) tell me straight out to do it and I don't think I'm going to remember what they've said, I'll write it downI try to go over it a couple of times in my mind. Try to memorize it.

Furthermore, Janice recounted experiences that were helpful for her. When Janice discussed her problems with peers during her school years, she mentioned that a way of coping was being involved with sports "*I totally was involved...I was always active in sports and stuff; that kind of kept me going*". Janice's involvement with sports was a source of positive affirmation. Other things that helped Janice was one-on-one assistance. In elementary school Janice had a tutor. In grade 9, Janice received learning assistance and a positive connection with the teacher's aide proved beneficial "*the lady that was helping me was doing really, really good....in Grade 10 my marks were improving.*" Janice went on into a work experience program that allowed for further one-on-one attention. The practical instruction and experience seemed to be successful:

*In Grade 10 they had a work experience program...I went in it and worked...I got an extended couple of weeks cause I was doin really good.
(Janice)*

This positive learning experience lead Janice to feeling more motivated and in fact turned into paid employment:

I asked if I could work and come in on Saturdays...if I came in and volunteered time would I still be able to do it just for the experience....so I kept doin it for months and he (employer) started payin me.(Janice)

Similarly Brenda discussed the benefits of one-on-one assistance. In her case Brenda received

help from her mother when she experienced problems with comprehension during a work training program:

I'd take the notes off of them (classmates) and come home and my mom would help me with them, like she'd read like a sentence, and she'd ask me, do you know what that means or do you know how that works, and stuff like that, and I'd explain back to her, and she goes well you just got the meaning of that question, and then she'd ask me another question, and she'd, she'd work through it with me, and then that would totally help me. (Brenda)

This interchange which occurred between Brenda and her mom, demonstrates what is necessary in order for Brenda to comprehend what she is learning. Concrete, specific, step by step learning within the dynamics of one to one assistance, certainly made a difference. I believe the questions which Brenda's mother asked were integral to comprehension "*Do you know what that means.....do you know how that works?*" These questions helped Brenda to conceptualize and verbalize what was going on for her. The process of checking back and forth with Brenda kept her focused and on track, allowing some success to manifest.

Brenda also discussed the use of visual aids "*I have to see something to remember*" and also talked about computers:

I thought I'd never be able to work on computers, I thought that it would just be like way over my head. But I worked in this one salon that you had to work with a computer and I just loved it.

Similar to Brenda and Janice, Roberta discussed that "*I'm better off being hands on and*

learning that way". She also went into a school program called pre-employment. She was able to work at her own pace and believes that *"if it wasn't for that course I probably would not be here with a job"*. Ted also discussed his work experience program at school:

I was in work experience for grade 11 and 12, on a job site, and that helped quite a bit.

Comprehension difficulties still occur for Ted but he has become comfortable in asking a lot of questions and getting more details for a given situation so that he can understand and make better decisions:

If I don't understand something I'll ask, and if I don't understand what they're saying I ask them for more detail so that I can understand.

Consequently, Ted has been able to hold onto a good job for the past year. It is the type of job which is structured and predictable. External structure seemed to help the participants.

Roberta stated that a structured home environment was very beneficial:

Our family has been really structured. (Mom) always had steps for us and it's always made it easier for us....you just automatically do the things you were always taught to do, so it, just seems to make it a lot easier.

The externally imposed structure seemed to help Roberta organize her self. The benefits of structure were seen when Roberta discussed her job. Like Ted's job, Roberta's place of employment is quite structured and this allows Roberta to do better:

I think I would need to have that (structure) because I find if I didn't then I'd be coming in the morning, going okay, well, what shall I do,

what can I do. The place looks fine, okay, well I'll just sit here until somebody needs me.....that place is structured for me.....if not, I would tend to do what I wanted to do....I would get preoccupied in doing something else.

Roberta also accepts the fact that sometimes an external cue is required from people around her so that she can notice her own elevated levels of behaviour:

My parents come in and have to tell me, "you need to settle down".... every once in a while they do tell me that...I don't see any harm in that...I don't see it as if they're treating me like a child or anything, it's just, I may not be aware of it.

Roberta reflects that she may not be aware of her own behaviours, and therefore does not mind some assistance. Given the tendency to get distracted or become impulsive, the participants have to work extra hard at being successful in the world if there is no external structure to guide them. For Brenda, in order to be more successful at life she must always be aware of her cognitive limitations, particularly the tendency to not comprehend cause and effect:

I, I really try; try hard to think twice about things that I'm doing or what I'm going to do, because not thinking about what I'm going to do can cause trouble.

Brenda's quote demonstrates that extra cognitive efforts have to occur in terms of thinking about the steps she chooses to take in situations. From my perspective, external structure and/or cues may help relieve some of the extra stress related to constantly trying to think twice about things.

Thus the participants indicated some clues as to what assisted them given some of the cognitive difficulties FAS/E brings. Active learning opportunities such as, working at their own paces with hands-on or visual methods, one-on-one attention, working and living within structured environments, receiving deliberate cues from others, and, doing and finding things which they were successful at, were all things which participants declared as helpful in order for life to be less troublesome.

External Support

The participants presented a wide range of complexities inherent within the nature of alcohol related birth defects. Therefore support which involves community and family collaboration becomes a major consideration. The third property of **What Helps**, is **External Support**. **External Support** was broken into three elements of support: **Family, Other Relationships, and Community Supports**.

Family Support

What emerged in the analysis of the data was a portrait of support which presented a heavy emphasis on family. Hence the family as support was a component recognized and acknowledged by the participants, and appeared as a thread woven throughout conversation. What I discovered through the voices of the participants in this study, was that their family system represented a huge piece of their support resource. For the participants in my study, either their immediate or extended family, provided an important source of nurturing which seemed to make an enormous difference to their feelings of self-worth and their varying

degrees of successful management of their disability. Throughout the conversations I had with each participant, I heard voices which articulated a respect for their parents and the role which they played and continue to play in their lives in terms of support. The participants' voices reflected their family's commitment and love. Family support appeared crucial to the participants and for most there seemed to be a heavy reliance on parental involvement. Beyond nurture, the participants' family support consisted of transportation, provision of finances, assistance with money management, shelter, counsel, or environmental structures. These continued beyond the developmental age when successful independence in these areas would normally occur. Evidence of this theme will now be presented.

Four of the five participants did not feel ready to leave their families for life on their own all though they were at ages where leaving home would be appropriate. Roberta shares her thoughts and feelings about this:

I've had people come and ask me, you know, Roberta, let's go move out, you know, we should go move out, and I'm like no, I'm not ready. It's like, I know that I'm not ready now....it's just like, even people when they ask me, I sit and think, away from my parents? NO!!! Not right now!

Roberta went on to tell me that there are things that she still needs to learn, particularly budgeting money etc. and therefore staying home is a current necessity. Ted gives similar reasons for remaining at home:

I've realized I'd like to stay home, not as long as possible but just until I have a better paying job and I've got my money management down.
(Ted)

Ted further states that he requires his family to assist in the area of money management:

*I just blow it (money) you know, right away....I want to budget, I try.
I have a bank account....it's a two signature account, so I have to get
two signatures.(Ted)*

Ted sees this externally imposed structure around his finances as a necessity for him to learn good money management.

Janice discussed being uncertain about moving out on her own:

*I guess in a way I'd probably worry about how I'd make it on my own,
so it's all fine and dandy to have this, but if it's your place you have a
bigger responsibility. (Janice)*

Teresa is supported in a community environment assisting the mentally handicapped. She recognizes in herself that she requires support "*I don't have a lot of independent strengths*".

It should be mentioned here that Teresa "qualifies" for community support because she is mentally handicapped. Therefore there is less pressure on her family. Her resources include support groups, residential support, work programs, a personal counsellor, and group recreation opportunities. These types of support measures are not available for FAS/E individuals who are not mentally handicapped. The long-term measures of responsibility fall on their families.

The comments which I heard from the participants reflected a dependence on their parents

and a reliance on their family's environmental structure. Despite their chronological age, these participants identified an internal ongoing need for external supports and structure.

Brenda emphasized the following:

Some parents might think that because they (FAS adult children) are adults, they can manage themselves....well they can't....and they might put off that they can but they won't...they (parents) have to be behind their child no matter how old they are especially if they have FAS (Brenda).

Brenda's honest admission of the need for on-going family support, raises issues about the problems FAS/E adults may have living independently, and the responsibility this generates on their families.

In addition to the practical measures of family support, the participants reflected how their families nurtured their emotional needs. Roberta reflected upon the support from her parents in terms of their ability to encourage her to succeed and move forward, yet allowing dependency when needed:

*If I need the help, well then I can always go to my parents cause I know that if, if I do start to fail, I know for a fact that they will not let me...because without them, I wouldn't have gotten this far.. ..it's like they have slowly but surely been pushing me this far to succeed, and I know they want to see me succeed all the way.
(Roberta)*

In the quote above, Roberta expressed the importance of encouragement, particularly parental encouragement, and similarly, Brenda endearingly describes the importance of the

relationship she has with her mother. While their relationship has had many difficulties, largely because of what Brenda described as her own inappropriate behaviours, it was clear from our discussion that family support meant the world to Brenda's feelings of self-worth and personal success as she rode the roller coaster of FAS. Brenda spoke with pride and pleasure about her mother and I received the impression that she was quite a lifeline for Brenda:

My mom's really helping me...when she's here I can talk to her....I love her to death....my mom is very, very, special to me. She's just, she's done so much for me, she's stuck beside me through everything.... she understood.(Brenda)

Brenda also described the role of advocate her mother took on when Brenda was having tremendous learning difficulties as a child in school:

They (school professionals) said that I'd never learn how to read, and my mom said "if you don't teach her how to read then you guys are gonna be livin with me 24 hours a day, 7 days a week, in this office cause I'm not leaving!" And that got through because I got help and I learned how to read. But mom still used to sit up with me, like, all night, sittin there teaching me how to read.(Brenda)

Roberta discussed the supportive and understanding nature of her parents when she was struggling in school:

I was always failing subjects...and it would get real frustrating because I'd be trying my hardest and everything but no matter what, it was just, I would not pass. But my parents have always told me as long as I tried my hardest then it doesn't matter what grade I get.(Roberta)

Considering the impact this disability has upon self-esteem, encouragement from family becomes critical. For Roberta, support from family also meant that questions about her disability were able to be directed to her parents, knowing that her questions would be dealt with honestly and supportively. Being heard meant that the questions Roberta had about her disability would not be trivialized or ignored and allowed Roberta to develop a better understanding of her disability:

It's always been like, if I've ever had questions (about the disability) I was always able to go to my parents and ask...if I was wanting to know anymore about it, I would be able to ask my parents.

Ted also stated that his parents are a source of support for him and that FAS adults who don't have family supports would likely experience "*loneliness. A hell of a lot of frustration*".

Thus, the participants described families who protected, assisted, advocated, taught, and supported them wherever and whenever possible. There were indications that this support was also very necessary even though the participants were adults. The long-term commitment necessary for these individuals raises questions about the reality of family alone being able to adhere to this commitment, without a significant drain on energy and resources. Brenda relayed concerns about her future, her ability to succeed without her parents assisting her:

My parents aren't going to be here all my life, and I will probably have lots of troubles with FAS when I get older and, when my parents aren't here I have no one to turn to. So, I mean my mom won't be there for my support, so I need someone there or I need more knowledge

on how to control myself with every, every bit of it (FAS).

This poignant and honest acknowledgement of Brenda's need for her parents speaks a stark reality about the heavy dependence the participants have on their families, and their underlying fears regarding the removal of family support. In her account, Brenda speaks to the fact that when her parents are not around, she has no one to turn to. Brenda illustrates that she either needs the external support or at least more knowledge about FAS which would assist her manage it's impact. Her statement sums up the importance of family support and the need for knowledge, but also the importance of the community to collaborate with the family and the affected individual. When there is such long term reliance or family/parental involvement, the need for community assistance becomes even more important. Brenda is correct, her parents will not be around forever, and as a result, other support services need to be available and implemented while her parents are still with her.

Other Relationships

Two of the participants referred to the importance of **other relationships** as sources of support. Their statements indicate a reliance on relational sources of help in order to remember things or be responsible about things. Ted talked about his girlfriend being a major source of support influencing him in the right direction in terms of making better choices due to his difficulties making healthy decisions. She was "*quite a bit of help*" in terms of assisting Ted make better, safer choices for himself, and remembering the tasks which needed completion "*I'd kind of, say, forget things, and she'd be like my parents, oh, you've gotta, do this, you know, don't forget*". Brenda mentioned that another source of support for her

apart from her mother included her previous boyfriend "*I had a boyfriend for about four years ...he basically kept me under control*". While these experiences have luckily resulted in positive assistance and support for the participants, the implications of this kind of relational dependence reflects the participants' vulnerability to the good will of others in their lives.

Community Support

Providing knowledge about FAS to the affected individual and connecting that individual to resources can result in the relinquishing of the tremendous reliance on family support or other personal relationships. Broadening **community support** is then an important consideration.

Janice discussed the comfort of an informal friendship group for FAS young adults:

You can be yourself and not put on an act there. And they know why you are the way you are....I'm still learning about it and dealing with it (FAS) and figuring out like how other people with it deal with it, and what kind of problems they have compared to what I have.

Janice's statement seems to reflect the need for acceptance and understanding. In a group setting, the discoveries made about each other's similarities and differences confirm that our greatest sources of knowledge retrieved in an atmosphere of safety, can be in each other. In the group Janice was in, fetal alcohol affected young adults spent their time informally together while their parents learned more about various aspects of FAS in their own support group. While this was not a formalized group for the young adults, their connections with each other enabled sharing, humour, caring and support with friends who

are similar.

Lisa acknowledged that a support group is important and identified that one of her best sources of help was in a community based support group which met once a month to present information about fetal alcohol syndrome "*the knowledge helps me understand the disability*".

Brenda also indicated that support groups for individuals who have fetal alcohol syndrome or alcohol related effects are needed "*I think they need them....I think they should have them*".

These were the only statements the participants presented in regard to community support. For me, this again raises the issue about the heavy reliance on family. With the exception of Lisa, all the participants indicated that they received most of what they needed in terms of support from family and, that they would not necessarily seek out other sources of help because they had their families. Lisa was the only one who had access to a wide network of resources, thus relieving the onus of responsibility from her family.

The comments which I received from the participants in regard to what professionals need to know when working with fetal alcohol affected clients are stated below:

Have patience. Try to learn more about it (FAS).

Don't be so hard on them. (Ted)

Understand that I get distracted. (Teresa)

Professionals do need to know more about what the problems of the adults are, and how they can help them. Know about each different kind of thing that it (FAS) effects. (Brenda)

They're making it sound like as if it's some kind of new diseaseI just got a learning disability (Roberta).

They (professionals) should get to know as much as they can about it...it's becoming so publicized now...they should just know everything they can about it. (Janice).

The voices of the participants themselves indicated that their primary sources of support were family and friends. Included in these stories were references of a need for more knowledge about the disability of FAS. Thus the issue of support is an important one, and acknowledged by the participants as something which they require. This in turn raises serious concerns and questions about the longevity of support and what is required in order to sustain support during adulthood. As well, the participants point to the necessity of professionals gaining a better understanding of FAS/E. It appears crucial that the professional community develop strategies of support in conjunction with the families and friends of FAS/E adults.

Conclusion

The summary of the experience of FAS/E, based on the stories of the participants in this study, requires an acknowledgement of the challenges which occur for them on a daily basis,

and a recognition of their strengths and ability to persevere. The fast-paced, complicated, and excessively stimulating society in which we live, constantly tests the adaptive abilities of the participants. The participants' stories represent the courageous way they have maneuvered through the maze of this world, despite difficulties with memory and comprehension, decision making and hyperactivity. As adults coping with the deficits of fetal alcohol syndrome/effects, the participants were able to express their perspectives on how this disability has affected their self-esteem, and, importantly, what they require in order to develop a sense of success. The participants have clearly translated for me their perception of the world, thus informing my knowledge of FAS/E in a greater capacity. The themes which have emerged from the participants' stories represents their voices, and offers those who hear these voices an opportunity to respond to FAS/E in an enriched way.

CHAPTER FOUR:DISCUSSION AND IMPLICATIONS

This chapter will present the research findings with respect to establishing this study within the context of the existing literature by demonstrating how my findings support, add to and/or refute the existing literature on fetal alcohol syndrome. Implications for policy, practice and further research will be examined as well as the limitations of this study.

Existing Literature

This study was designed to gain further insight and understanding about the nature of fetal alcohol syndrome or effects in adulthood. Fetal alcohol syndrome (FAS) and Alcohol Related Effects are specific types of birth defects caused by a pregnant woman's use of alcohol. This study represents five individuals' subjective experience, four of whom were diagnosed with fetal alcohol syndrome and one who was diagnosed with fetal alcohol effects. Their voices of experience expanded my understanding of alcohol related birth defects in adulthood.

To date, most of the existing studies in regard to fetal alcohol syndrome or alcohol related birth defects, are quantitative, scientific or medical studies which focus on fetal alcohol syndrome or alcohol related effects in childhood and adolescence. Other studies focus on the experiences of the caregivers who have raised children who have either fetal alcohol syndrome or alcohol related effects. Essentially, the voices of the adults who have the disability are not well represented in either the research literature or popular literature, and thus a qualitative study of this nature certainly contributes to the existing body of literature. It has attempted to provide adults who are effected by FAS and alcohol related effects, an

opportunity to discuss their whole experience from their perspective, thus broadening and enhancing the existing knowledge of this disability. Thus, this study accentuates the participants' perspective; how FAS/E is perceived and felt by the adult individual who has this disability.

There are several points which emerged through the participants' stories which require focused attention and discussion. These are the following:

1. The participants expressed on-going cognitive difficulties. This played out in terms of memory, comprehension and decision making.
2. Frustration in terms of being understood and understanding the world resulted in an impact on self esteem.
3. Diagnosis was considered important but the participants reflected on both positive and negative aspects.
4. The participants' stories emphasized the importance of on-going support. This support is being given by their families. This places the burden of responsibility on families to maintain long-term support, even if it may not be feasible to do so.
5. Community support is lacking except for those adults who are mentally handicapped. Community support was not necessarily seen as personally relevant for the participants, but was considered important. This is largely due to the participants being content with support from family. However, community/professional expertise of FAS/E was seen as essential from the perspective of the participants.

I consider these points to be the highlights of the findings. Discussion of these points will

now be presented.

Cognitive Impact

In their own style and their own words, the participants in this study discussed how FAS has played out in their lives. Cognitive difficulties, such as problems with memory, tracking, comprehension and decision making were the first most noticeable components which emerged as the participants told me their stories. As I analyzed the data I particularly noticed that many of these difficulties were revealed as the participants talked about problems which occurred for them within the education system. More often than not, problems with school were spontaneously brought up and heavily focused on by the participants even though there was ample opportunity to focus on current issues in their adult lives. This indicated to me that their school lives had an enormous impact on them. Learning difficulties impacted their self-esteem levels and every participant noted more negative aspects of learning than positive.

This finding is consistent with the current literature. The type of classroom structure and educational placement can either bring about setbacks and strain, or, set the stage from progress and growth (Caldwell, 1993). Evensen (1995) states the following:

Traditional teaching techniques alone have resulted in frustration for students with FAS/E as well as their teachers. These techniques inaccurately assume that with minimal assistance the child is capable of taking in verbal instruction, processing the information, remembering what is expected, and completing the assigned tasks.(p.3)

Through the analysis of the data, I saw that the events which took place in the lives of the participants, could be interpreted as events which likely occurred because of disruptions to cognitive development. Various problems in terms of cognitive development were discussed by the participants, although they did not use the term “cognitive development”. Instead, they described problems with “remembering”, “understanding”, “comprehending”, “hyperactivity”, “distractibility”, “decisions”, “judgement”, “following”, “concentration”. One participant described FAS as “affecting your thinking” a statement which provides an information rich picture of FAS and it’s impact on cognitive processes. Interpreting the data, I understood these words and phrases which the participants used at certain times during their stories, to be an expression of their cognitive struggles.

These findings in regard to cognitive difficulties, specifically in the areas of memory, comprehension and decision making, are supported within the current literature on alcohol related birth defects. For example, Streissguth (1993) in reference to the long term effects of FAS, stresses that cognitive based behavioural problems are the primary cause of lifelong disabilities. The literature indicates that cognitive functioning such as memory retention, sorting and understanding incoming verbal information, comprehension, and understanding cause and effect, are impacted when the fetus is exposed to alcohol. West, Goddlett and Brandt (1990) refer to the memory difficulties of fetal alcohol affected persons. They state that hippocampal damage caused by alcohol to the fetus, disrupts working memory, which is short-term, context-specific memory, more severely than long term memory. Watson (1992, p.172) indicates that the hippocampal formation of the brain is particularly sensitive to ethanol and specific memory deficits have been observed through a variety of studies. Evensen (1995) explains that

Behaviours and specific sites of alcohol caused brain damage have been correlated; hippocampal damage has been implicated in learning and memory deficits, and damage to the cerebellum may affect motor control. (p.1)

Antonia Rathbun, who co founded the FAS/Drug Effects Clinical Programs in Portland, is a therapist who has worked extensively with FAS/E affected children and adults. In regard to the memory processes of affected individuals, she states that “individuals with alcohol related birth defects may have difficulty with several memory functions, though their long-term visual memory may be fairly good. They may routinely forget what they just read by the time they reach the end of the paragraph.”(Rathbun,1995, p.2). This is consistent with what the participants in my study described. The participants discussed problems with memory, seemingly short term memory and learning new information. In reference to FAS children, Rathbun (1993) also states the following:

Due to their memory deficits, children with FAS/FAE seem to be forever starting over on schoolwork, homework, or household chores. They know that last week they learned and understood it, but now they are at a loss to remember it. Both children and caregivers feel mystified and frustrated when skills they learned a week ago disappear and have to be relearned over and over, especially when the children know that they knew it, but now they cannot do it. (p.302)

Similarly, the participants in my study emphasized that learning was a chore and full of frustration because of memory and comprehension difficulties. The participants discussed forgetting about what they just read, forgetting instructions, getting distracted while performing a task, losing pieces of conversation, not understanding what they may have just

been taught, and difficulties taking notes. One participant noted difficulties in being able to grasp the larger concepts of things. This is consistent with Rathbun (1993) who indicates that the person who has an alcohol related birth defect, may grasp pieces of the big picture, but the pieces may not necessarily connect and form context.

Lefrancois (1980) states the following about the importance of memory in every day life:

Memory and learning are inseparably linked. We remember only that which we have experienced and learned, and the proof of learning is implicit in the fact that we remember. (p.250)

Lefrancois presents the importance of memory and that memory and comprehension are connected. If comprehension is disrupted, the ability to not only learn reading material, but social cues, rules, and life skills, can be greatly hindered. Indeed, the participants in my study presented situations where memory and comprehension difficulties were interwoven. The participants' stories reflected what life is like when comprehension is disrupted; when information has to be explained over and over and how difficult it is when you are not able to remember tasks or understand concepts when something intuitively says that you should because it's familiar at a certain level. Essentially, the words "frustration" or "frustrating" appeared numerous times throughout their stories. The frequent usage of these words demonstrated to me that the participants' problems with memory and comprehension presented a variety of difficult challenges. This is supported by LaDue et al. (1993, p.112) who found that the symptoms most characteristic of adolescents and adults with FAS/E are attentional deficits, memory problems and hyperactivity.

For the past 20 years at the University of Washington, a group of researchers have followed the progress of individuals with FAS from childhood through adolescence and into adulthood. Their research has found that cognitive deficits continue into adulthood. Some of the resulting impact is specialized memory deficits and poor judgement which becomes increasingly noticeable with increasing age (Streissguth, 1991). In my study, while there was some discussion about events in adulthood which reflected a continuing occurrence of the difficulties associated with disruptions to memory and comprehension, the focus of the participants more often than not, remained on their school years. Hence the participants did not note whether problems with memory or comprehension were increasingly problematic when they grew older, but nonetheless did state that these problems do continue to exist. They indicated that their high-school, adolescent years were the worst and this is consistent with Vadheim (1992) He suggests that "Adolescence is also the period of time when FAS is hardest to deal with, due to the surge of hormones, mounting peer pressures, and the inherent inability of the FAS child to understand cause and effect" (p.11). This then implies that the need for sources of support during this period of development is crucial.

DeVries and Waller (1995) discuss the connection between cognitive development and judgement reasoning, stating that FAS/E are disabilities which arrest cognitive development, permanently altering memory and judgement ability. Research indicates that fetal alcohol affected individuals do not link cause with effect or generalize information from one situation to the other (Evanson, 1995; Rathbun 1993). Olson, Burgess and Streissguth (1992) suggest that in terms of adolescent and adult development, individuals affected with FAS and FAE experience problems in the areas of poor judgment and impulsivity. In my research study, one participant stated that one of the worst things about having FAS, was

the difficulty in making good, safe decisions for herself. Another participant described problems related to FAE, which he termed as “poor judgement”. Their stories demonstrated difficulties in evaluating choices until after the consequences were evident. This is consistent with the research literature.

Memory is not an isolated skill, but rather a process intimately related to all cognitive processes including problem solving (Kail, 1979, p.127). The participants demonstrated through their examples that they often forget critical pieces of information which impacts communication with others, and, problem solving abilities. Kail (1979) indicates that the way information is encoded in the brain is critical for solving problems. The neurological impact of FAS/E interferes with the encoding of critical pieces of information necessary for skill development in the area of making decisions and/or problem solving. The participants’ stories reflected the impact of FAS on cognitive development and the interconnectedness of memory, comprehension and decision making.

Self Esteem

Dealing constructively with the issues of fetal alcohol affected individuals and developing appropriate external support measures becomes difficult if their presenting symptoms are not understood. The participants indicated that some of their behaviours were misunderstood. Rathbun(1993) found that a chronic history of accusation may leave residual fear of blame. This is reinforced through my findings as the participants talked about being seen as “lazy” in school, or being picked on by peers, feeling “stupid”, feeling “frustrated”. This is consistent with Rathbun (1993) who indicates that the slower cognitive pace of the FAS/E

individual is often misinterpreted as “lack of commitment and laziness” (p.301). This then points to the increasing significance for education, social service, mental health and other agencies to develop an understanding of the critical factors related to FAS/E and the individuals who have this disability.

Indeed the participants indicated through their stories a tendency to individualize the disorder. Inevitably self-esteem was impacted in one way or another for the participants in my study. Feelings about the self indicated that throughout childhood confidence was eroded, many feelings of helplessness and frustration occurred, and getting into trouble was not unusual. “What’s the point in trying” was a message given by a couple of the participants. This is confirmed by Rathbun who states:

**Symptoms may interfere more on some days than on others.
They don't know what is wrong, and say “I'm just stupid”.
Frustration of their efforts erodes confidence and causes low
self-esteem. They learn how to hide and try to get by because
they may not understand exactly what is going wrong; they
run into difficulty putting it into words; they experience
frustration when others misinterpret their difficulties.**

Society especially values those persons who demonstrate initiative, control, dependable, consistent, and on-task behaviours (Rathbun, 1993). These values can undermine the self worth of individuals who have FAS/E because they cannot possibly live up to these kinds of standards. Inclusive in these values are societal expectations of conformity which create enmity, rather than solutions which could incorporate the individuality and pace of the

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FAS/E affected individual.

The participants indicated that they did not want to be seen as “different” but they did want to be understood in light of their disability. This then points to the necessity of understanding the cognitive strengths and weaknesses pertaining to an individual who has FAS/E. The participants spoke of being misunderstood. They related incidences where they felt that they were trying their very best, however, others around them could not perceive their efforts that way. This was largely because the participants’ behaviours were not placed in the context of FAS/E.

In my research study, context and meaning for the problems the participants were experiencing did not really surface until after they received a diagnosis. They finally understood what was “wrong”. Therefore, in order to minimize the misinterpretation of behaviour related to FAS/E, it becomes extremely important to reframe the presenting behaviours in light of the diagnosis of FAS/E. Once others realize how alcohol related birth defects manifest, then differentiating between deliberate behaviour and incompetence is much easier.

The following chart (Evansen, 1996, p.15) helps explain common misunderstandings of fetal alcohol affected individuals. Although the chart’s application is for students, it can be generated to working with fetal alcohol affected adults as well. The chart positions behaviours that have been described as typical to individuals who have FAS/E, in light of how these behaviours have been misinterpreted.

<u>Behaviour</u>	<u>Misinterpretation</u>	<u>Accurate Interpretation</u>
non-compliance	*willful misconduct *attention seeking *stubborn	*difficulty translating verbal directions into action *doesn't understand
repeatedly making the same mistakes	*willful misconduct *manipulative	*can't link cause to effect *can't see similarities *difficulty generalizing
often late	*lazy, slow *willful misconduct	*can't understand the abstract concept of time *needs assistance organizing
not sitting still	*seeking attention *bothering others *willful misconduct	*neurologically based need to move while learning *sensory overload
poor social judgement	*poor parenting *willful misconduct *abused child	*not able to interpret social cues from peers *doesn't know what to do
overly physical	*willful misconduct *deviancy	*hyper or hypo-sensitive to touch *doesn't understand social cues regarding boundaries
doesn't work independently	*willfull misconduct	*chronic memory problems *can't translate verbal directions into action

An examination of the above chart reveals the tendency for individuals who are in contact with FAS/E individuals, to view some of their difficult behaviours as “deliberate” or “willfull”. The chart reinforces the necessity to understand FAS/E in context, and modify

expectations.

The Diagnosis

The process of diagnosis for some of these participants helped explain the cause of their difficulties thus relieving some of the burden for themselves and others (primarily their parents) who were in relationship to them. Diagnosis, for chronically ill family members, even if recovery cannot take place, has been noted to bring a sense of relief and renewed energy for problem solving (Simon, 1988). This research study seemed to reflect that this also was the case for most of the participants and their families. Diagnosis appeared important to most of the participants and is part of this problem solving process as it allows for greater understanding of the self through a reframing of perceptions. Indeed, the participants in my study reflected upon some of the feelings of relief they experienced upon finding out the root reasons behind some of their behaviours which produced conflict for themselves and others. Malbin (1993) suggests that a diagnosis allows for a shift in how the problem of FAS is seen; from behavioural to organic, allowing patterns of behaviour to make sense thus eliminating feelings of guilt in the affected individual. The prevailing message from the participants in my study was that diagnosis for the most part is positive, leading to a greater understanding of the self and development of management of the disability.

Two participants however, brought up some very interesting points about how the diagnosis can stigmatize and be pejorative. Traditional models of diagnosis present a diagnostic process which transfers power to define an individual into the hands of helping

professionals. It focuses on weakness and not strength. For these two participants in particular, the diagnosis initially created a sense of disempowerment and uncertainty. The diagnosis came across as a dehumanizing force, creating a label. The participants felt diseased, retarded. One participant was very angry at doctors who stated she would not have much success in her life. A diagnosis can distort the helping professional's vision so that distressed behaviours are pejoratively categorized (Brown, 1994). This highlights a problem for practitioners in that the well-intentioned use of an exculpatory label, serves to place the labeled person in some jeopardy of victimization because of the assumptions the label carries (Page & Day, 1990).

Even with a diagnosis, if it is not explained exceptionally well, the diagnosed person may not have an accurate understanding of the disability. Three of the participants demonstrated some difficulties in this area. To me, these difficulties suggest that communication with individuals who have FAS/E must be concrete rather than abstract, particularly when communicating around diagnosis. Streissguth et al (1991) research of 61 adolescents and adults concluded that 62% had significant levels of maladaptive behaviours which included lower comprehension and abstraction abilities. Therefore, from the stance of a professional how an FAS client makes sense of information presented to them, becomes a critical part of the helping process. This requires important consideration, particularly when dealing with FAS and alcohol related effects because there are so many inconsistencies between the affected individuals.

Inherent in this is the necessity to work carefully with the identity, feelings and comprehension abilities of the FAS/E individual. Statements from some of the

participants, describe their need to be recognized and understood as having differences, but still be considered the same. This dual message which came across as contradictory, actually reflects the dilemmas involved when generating interventions, and, the complicated feelings in the hearts of those who struggle with FAS/E.

The Issue of Support

It became apparent to me during the analysis of the data, that the childhood/adolescent years of the participants reflected enormous struggles and strains on all of the participants. However, at the same time I was somewhat surprised at the overall positive outlook of the participants as adults. Most of my participants seemed to feel more in control and less overwhelmed by the FAS in their adult lives.

During the time I conducted the interviews, the participants were in current situations which were far less stressed than when they had to attend school and learn new information on a daily basis. Even though the participants emphasized that they required external structure in order to remain focused and organized, be it at home or on the job, and, discussed other areas of on-going difficulties, their stories of how they feel about themselves now, compared to how they felt about themselves growing up, reflected a greater sense of positive feelings. The literature however indicates that “adolescents and adults with FAS/E commonly suffer from low self-esteem....and are at risk for serious life problems including depression, suicide, alcohol and drug abuse” (AADAC, 1994). My findings certainly demonstrated the struggles the participants experienced with their self-esteem during childhood, adolescence and adulthood, however, the participants all alluded to a more overall positive sense of self

and outlook now that they are adults. My struggle to make sense of this took quite a while. At first I thought that they were minimizing current struggles as adults. Finally I realized, that because all of the participants lived at home, with parents, or, in the case of Lisa, in a independent supported environment, this in all likelihood, significantly decreased the tendency for external stressors related to independent living, to impact them in serious ways. The on-going family support and direction, coupled with the removal of school as an external stressor, seemed to contribute to the general, more positive outlook of the participants in adulthood. Even Janice, a participant who stated that life for her is still an on-going battle, acknowledged that the school years were the worst. This then raises two issues: one, the tremendous stress related to the education system and learning (previously discussed in this chapter), and two, the issue of support, particularly family support, which I consider one of the most important findings which impacted this research study.

My research study indicated that the family was delegated as primary providers of support. The participants presented stories which reflected a tremendous family reliance. The finding of family support, evident throughout the participants' stories, was a contributor to feelings of well-being for the participants during adulthood. The participants described their families as caring, supportive, protective and their strongest advocates. In this study every participant stated that they were not yet ready to live on their own, and that they still required the support of the family environment.

This intense need for support is consistent with other findings. For example, Streissguth (1991) research on FAS/E affected adults, found that adult persons who have FAS/E have difficulties with self-sufficiency. Jones (1992) refers to FAS adults as having an inability to

provide self-governance and indicates that the atmosphere in which persons who have fetal alcohol syndrome lives, can influence their behaviour. Streissguth, et al (1996, p.4) in her study regarding fetal alcohol syndrome and secondary disabilities in 415 affected adults, demonstrated that one of the strongest factors which emerged as universally protective in terms of secondary disabilities, was "living in a stable and nurturant home of good quality for over 72% of life" (Streissguth, et.al 1996, p.5). My impression of the participants is that they felt more successful as adults because their current environments remain structured and consistent, stable and protective. However, this also raised concerns and questions regarding the prognosis when FAS/E adults begin living outside of the family home.

Some informal discussions I had with adoptive parents of fetal alcohol affected young adults who are living independently, supported the participants' perspective regarding the importance of family support. Several stated that their adult children feel like they are living independently when in fact they receive considerable support with things such as, banking, purchasing groceries, transportation to doctor's appointments etc. These parents confirmed that problems with memory, comprehension and poor decision making are clearly evident from their point of view and hinder total independence. One parent described the tremendous successes their FAS foster son developed during his long-term placement with them; he graduated, had a job, had savings in the bank etc. However, upon the age of nineteen, and discharge from the support of Social Services (i.e. his foster family), this young man lost his job, his savings and developed a drug habit, all within the span of a three month period. This is not uncommon, according to Streissguth (1996):

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. They should be given an appropriate level of societal protection and support. To do this, their primary disabilities must be better understood by families, service providers and by society at large.....by understanding the devastating secondary disabilities that characterize most individuals with FAS/FAE and by understanding the intrinsic and extrinsic risk and protective factors that exacerbate or ameliorate these disabilities, we should be able to improve the quality of life for people with FAS and FAE and their families, and to reduce costs to society. (p.8)

While the participants presented stories which reflected a tremendous dependence and reliance on family, I felt that there was an undercurrent of tension which created a dissonance between wanting or having the support, yet also having independence, or being seen as independent. There was a need for control/expertise over their own lives versus their need for family support. LaDue (1993) describes this as a tension between wanting to have a normal life and what can be safely achieved. None of the participants wanted to be seen as "different". Hence this presents a bind, because being affected by FAS creates certain inevitable difficulties, which the participants themselves clearly expressed. Treating individuals who have FAS/E like "regular people" (as one participant described it) can create scenarios and situations for them which can develop devastating problems.

When the participants discussed their reliance on family, one participant in particular discussed concerns about what could happen if family was no longer present. While I was impressed with the descriptions of family cohesiveness, I am concerned about the heavy reliance on parents for what becomes an undetermined amount of time. The following chart provides a profile of a developmental timeline (maturation) for people with FAS or FAE

(FAS/E Nation, 1995, p.7):

<u>Age of the Individual = 18 years</u>	<u>Skill</u>	<u>Developmental Age level</u>
	Expressive language	Age 20
	Comprehension	Age 6
	Money Concepts	Age 8
	Time Concepts	Age 8
	Emotional Maturity	Age 6
	Physical Maturity	Age 18
	Social Skills	Age 7
	Living Skills	Age 11

The above guide provides a sense of the long-term commitment necessary for these individuals. It is a societal expectation that the family shoulder the responsibilities of caring for those who require it, particularly in light of the current depletion of governmental support and services (Aronson, 1985). The statements of the participants indicated that their families protected, assisted and advocated for them whenever possible. However, there has to be a balance between family responsibilities and community/government assistance otherwise the depletion of family energy becomes a reality and the FAS affected individual is abandoned to their own devices. McPhee (1992) indicates that services beyond the reserves of the family are essential for FAS/E young adults: "Most young adults with FAS/E have immense problems living independently. This puts a tremendous burden on their families."(p.48) A successful transition into the requirements of adulthood and independence requires careful planning and collaborative on-going supports beyond the family itself (See Appendix "I").

Physical and emotional exhaustion is a reality for families (one of the participants briefly discussed having to go into a foster home for a brief period of time during adolescence), and

requires external support measures. It is not unusual for families where FAS/E is an issue, to use up all their emotional and physical reserves (DeVries, 1996), thus creating a sense of hopelessness for both the FAS/E affected individual and their caregivers. It should also be noted here that there is a high prevalence of FAS/E affected children in foster care.

Winquest (1995, p.9) suggests that children affected by FAS/E are over represented in foster care and children placed for adoption, and, that FAS/E is probably the most common factor in adoption and foster parent breakdowns.

In a study of 61 adolescent and adult FAS/E patients, LaDue et al. (1992) suggests that the most salient problems experienced by these individuals, (i.e. impulsivity, poor judgement, poor social skills, difficulties organizing and setting boundaries) are minimized (not eliminated) "in tightly structured homes with vigilant parents." (p.125). Vigilance, is the key word here. Vigilance takes energy, stamina, creativity and access to resources. An important point to consider here are the potential issues regarding homes where the structure is not so vigilant, or cannot remain vigilant. This represents many stressors and huge expectations on the part of family. In the case of birth parents, guilt issues may interfere with the process of finding support, or, if alcohol consumption continues, the added chaos can further hamper the development of FAS/E individuals. If tight, continual, structured support is a necessity for FAS/E individuals, then the longevity of the burden on families is immense. The participants themselves referred to the necessity of external structure and cues. All these considerations re-emphasizes the concern of what happens when these affected adults are living independently.

In summary then, the findings of this study present relevant information which expands the

current understanding of FAS/E in adulthood. The voices of the participants themselves give an account of FAS/E beyond pathological categorization which has normally been determined by caregiver reports and psychological measures. The findings of this study relayed how FAS/E impacts cognitive development and self-esteem from a perspective which portrays the participants' own feelings and descriptions. This is important because the participants' words illuminates with greater clarity, how they think, feel and what they need.

The information provided by the participants in this research study presents implications for further research which could attempt to illuminate both barriers to identification and gaps in services to FAS affected adults which currently exist throughout professional communities. The information provided by the participants in this study about their experiences with FAS also provides some insights with respect to implications for practice and policy. These practice and policy implications will now be addressed.

Implications for Practice

The participants raised my awareness of practice and policy involving FAS clients, and their descriptions of their life experiences highlighted the need to look at services. First of all, a major consideration for professionals who may be working with persons who have an alcohol related birth disability, is the fact that effective treatment involves a better understanding of the disability. A major hurdle which needs to be overcome, at least at the tertiary level of prevention, is the recognition of FAS/ARBD as a possibility in some of the clients the community serves. One of the participants stated that she had been sent to various counsellors since she was five years old, but none of them knew about fetal alcohol

syndrome. She is currently trying to find a suitable counsellor who specifically understands FAS/E. Given the cognitive issues which the participants in my study presented, services which have approaches that engage in insight therapy or demand that clients demonstrate initiative in organizing their own support system and follow through appropriately with recommendations, will more than likely be working with a strategy which is not tailored to the special needs of clients who have FAS/E.

Without an understanding of the developmental profile of FAS/E, this disability remains hidden in a variety of ways. The participants indicated through their experiences that they have been misunderstood by others in relationship to them. They have even at times misunderstood themselves. They may have appeared to understand more than they actually did. Therefore this presents certain implications for practice. One professional who understands FAS told me that from her perspective, other professionals who are not knowledgeable about the disability, simply see the behaviour and assume the person has an "attitude". They do not realize it is the disability at work. Therefore, in-service staff training on the implications of FAS and alcohol related effects is a must. During intake interviews, staff should be trained to consider FAS when appropriate clues are present, particularly from social history. This should be incorporated as standard practices for all types of social service agencies, particularly those who are involved in dealing with families where alcohol usage is a major factor. The practitioner can then switch gears in terms of practice methodology. The type of communication and treatment which must be done with an FAS client must allow for such problems as attentional deficits, distractibility, memory difficulties, difficulties in making transitions or safe, sound decisions, difficulties in predicting consequences for behaviours, and inability to problem solve or pick up social

cues. For example, I noticed that during the interviews I conducted with the participants in my study, I had a tendency to “get lost” in the maze of information the participants presented. Sometimes, the participants would switch topics in the middle of topics and therefore getting back on track and focused was a feat in itself. Sometimes the participants had difficulties elaborating on an idea they presented. I found that I frequently experienced feelings of frustration, even though I knew that this was about FAS/E and not the interview. Lost in a maze is what it can feel like for both the client and the therapist as they attempt to sort out issues.

Insight therapy is not necessarily going to work. The participants in my study indicated that visual aids assist their problems with memory and tracking information. They also indicated that hands-on, reinforced, structured learning allows the individual to retain information in a more successful way. As well, there is a need for the practitioner to receive input from the client’s support system in order to obtain a complete picture of the client’s position.

Sometimes the client may not be able to express what is going on. The challenge for the practitioner is to find new ways to have the concepts they are trying to impart to their FAS client, as making sense from their perspective. This requires a creative way of providing help or doing therapy. Continuity in personal practice as well as community practice, in terms of treatment strategies is also critical. This again requires a developed understanding of the nature of FAS/E. The FAS/E individuals in my study indicated that they do better in structure and routine. This reinforces the need for practice strategies to begin from this point.

Despite the increased attention towards fetal alcohol syndrome and alcohol related effects

fetal alcohol syndrome and alcohol related effects can be easily overlooked and certainly not even questioned as a possibility. When I was trying to find participants for this study, I approached a couple of Adult Children of Alcoholics (ACOA) group co-ordinators. To my surprise they told me that FAS is not at all discussed in their groups. One co-ordinator informed me that if she were to bring it up, it would not even be well received. I found this extremely curious. During my review of the research literature I noted that the characteristics of FAS/ARBD individuals is strikingly similar to the noted characteristics which Woititz (1993) presents as characteristics of the adult child of an alcoholic:

Fetal Alcohol Syndrome/Alcohol Related Birth Defects (Adulthood) Noted Characteristics (Streissguth, 1991)

Attentional Deficits

Lower Average IQ Performance

Depression

Easily Distracted

Impulsivity

Poor Judgements

Memory Deficits

Difficulties in Making Transitions

Adult Children of Alcoholics Noted Characteristics (Woititz, 1983)

They guess at what normal behaviour is

They have difficulty following a project through from beginning to end

They lie when it would be just as easy to tell the truth

They judge themselves without mercy

They have difficulty having fun

They overreact to changes over which they have no control

They have difficulty with intimate relationships

They constantly seek approval and affirmation

They usually feel they are different from other people

They are impulsive. They tend to lock themselves into a course of action without giving serious consideration to alternative behaviors or possible consequences

They are super responsible or super irresponsible.

At a quick glance to the above generalizations, one can see that most of the characteristics common to individuals who are ACOA, are also in common to individuals who have FAS/E. It appears that the ACOA movement has not considered the ramifications of FAS/E as possibly contributing to difficulties in some cases. In fact, consideration of neurological issues rather than just environmental issues would change their treatment approach and would in fact have tremendous ramifications for the movement.

It is time that further consideration of the neurological impact of alcohol be included when assessing the consequence of alcohol abuse within the family. My impressions are that adults are living with this disability and don't even know it. The participants demonstrated how this disability impacted their self-worth, particularly when they didn't know they had it. Their behaviours didn't make sense and self-blame was the norm. I can only imagine how many adults unknowingly live with this disability and have feelings of self-contempt because efforts to change what cannot be changed have been unsuccessful.

Diagnosis then plays a vital role in the lives of individuals who have the disability of FAS. Diagnosis at least explains the cause of certain problems and provides more statistical evidence for researchers and those lobbying for money for programs to assist those with the syndrome (LaDue, 1990). Despite this however, there are tremendous difficulties in terms of obtaining an actual diagnosis, particularly for adults. In British Columbia, there is very little

help available in terms of diagnosing adults yet the data in my research, as well as the data in the current literature, indicates that diagnosis is an issue which cannot be ignored when attempting to assist individuals with a disability such as FAS. I discussed the issues around the needs of FAS adults, with the FAS/E Support Network of B.C. To date in British Columbia, there is no formal means for diagnosing FAS in adulthood. There is a very high demand for this service but nothing is in place. There have been efforts to try and establish a clinic in the lower mainland. A formal clinic requires physicians who specialize in genetics, dysmorphology and pediatrics. To do a proper diagnosis, at least one to two hours is required. Currently there is no coverage under the medical plan for the diagnostic process.

In summary then, there are several implications for practice which reflect the necessity of taking a rehabilitative approach when working with FAS/E individuals. This involves a re-thinking about practice environments and strategies. Major hurdles to overcome involve:

1. developing an accurate understanding FAS and other alcohol related disabilities within the field of social work and education, two primary fields of service highly involved with FAS/E, yet lacking much knowledge and research.
2. developing better practice frameworks in service agencies
3. generating further public awareness
4. developing diagnostic clinics and a wide variety of support services for FAS/E adults

Limitations of this Study

This study, although providing an opportunity to broaden the understanding of fetal alcohol

syndrome and alcohol related effects, does have some limitations which narrow the scope of the study. I believe that my study only opens a door to the nature of understanding FAS adults. One of the limitations of this study is that it doesn't capture the depth of FAS and alcohol related effects in adulthood. While my study successfully presents the voices of FAS/E adult individuals and begins to bridge the gap in the lack of social work research in this area, the limitations which will now be described, concretely demonstrate what is required for future research of this kind.

First of all, there is a need during the research process, to keep going back to the participants, because of their difficulties explaining their perspectives. This is a necessity which needs to be built into the research design via multiple interviews. If we are to successfully give these individuals a voice which is well understood, some participants may need to be interviewed as many as three times. Second, further insight would have been achieved if I could have interviewed a more diverse number of participants and included those who are actually living independently. Given the difficulty in acquiring participants for this study, the focus had to become more narrow. Had I been able to have a more diverse sample, there would have been a greater depth of insight and a more developed representation of FAS in adulthood. The homes in which participants of this study lived, provided much support, guidance, structure and careful monitoring. My study provides no information on FAS adults who do not live in this kind of environment.

Having worked with FAS children and adolescents as a counsellor and as a foster parent, I have had "in my face" experience of FAS on a daily basis for about two years. I am very well acquainted with the difficulties the disability presents in this age group. Knowing that

this disability does not disappear, I carried with me a tremendous curiosity about how the disability operates in adulthood and I wanted to hear about the disability from the affected adults themselves. I believe I made every attempt to understand the disability from the perspective of the participants, however, I must acknowledge that my own strong beliefs with respect to concern about the development of these individuals had an influence on the study as a whole. I had many difficulties staying with the participants in their story, and not looking for their voices to support "my story". This tendency to "professionalize" the issues was a struggle which required continual discussion with my advisor in order to minimize this tendency. However, soliciting clarification from the participants during second interviews reinforced their voices and minimized mine, thus proving to me the absolute necessity of multiple interviews and extended time frames in which to do the research.

I have then several recommendations for future research:

1. Due to the lack of research in the field, further qualitative research involving the nature of FAS and alcohol related effects in adulthood, is absolutely essential. Research needs to focus on the experiences and needs of those adults affected by FAS/E by hearing and establishing their voices via multiple interviews. My research only involved adults who were not living independently. Given my findings regarding the participants' dependency on family, further research needs to focus on adults who are living independently as single adults, and, as parents. Two groups should be examined; those who are connected to supports, and those who are not.
2. Further research regarding developmental stages of individuals who have FAS is needed.

This could include for example, looking at the potential stressors during the ages of 18-25 opposed to 25-30, and examining how or if adaptive functioning is integrated. My research focused on individuals who were 25 and under. Much of the discussion involved the impact of FAS/E during school years. This also raises questions regarding the education system and FAS/E.

3. This research study raises further questions into the meaning of diagnosis for FAS adults, such as “What are the difficulties in obtaining a diagnosis?” The participants described both the positive and negative aspects of diagnosis. Further research which address questions such as “What are the differences between receiving a diagnosis in childhood opposed to adulthood?” and, “What are the implications of diagnosis if there is no family support?” and, “What are the implications of the diagnosis, particularly in terms of FAS/E parents, whose parenting skills are being evaluated by Social Services”. These questions all have important implications.
4. Two participants briefly discussed the issue of medication. I believe that this is an area which requires further exploration in research and raises questions about the use of medications in adulthood in order to assist with adaptive behaviours.
5. This research study raises further questions into how to best help FAS adults in ways that are constructive and not destructive. Insight therapy is the norm amongst clinical services today. It is my sense from the participants’ responses, as well as from some of the current literature that insight therapy would have limited success. Instructive, practical in-home, life-skill supports are likely more useful.

6. I am conscious that research often focus on difficulties of the population group being studied rather than strengths. In retrospect, emphasis on what makes successes occur for these individuals would be important to develop in further research. It is important to continue to hear the voices of FAS adults in order that they may become more and more involved in their own advocacy efforts. The participants in my study clearly described what works and what doesn't work for them. It is hoped that further research can focus on strengths as well as weaknesses so that effective intervention strategies may be understood and utilized.

In summary, I believe that the findings of this study supported and enhanced the current, literature available on fetal alcohol syndrome and alcohol related effects in adulthood. The stories of the participants have broadened the scope of knowledge. The limitations acknowledged in this chapter, serve to identify issues which can enlighten future research studies in the area of fetal alcohol syndrome/effects. Due to the limited amount of available information on this disability, across all sectors of helping professionals, the knowledge incurred from the participants in my study provided the opportunity for professionals to be more informed in their practice, both at a clinical level and a policy level.

CHAPTER FIVE

Conclusions

As I review the work which has occurred in order to put this research project together, I am continually struck with how much more knowledge I need to obtain about fetal alcohol syndrome or alcohol related effects. I am left with more questions now, then when I started. My concerns about the potential outcome of individuals who have FAS during adulthood, still continue to exist, particularly in light of the service delivery crisis in our province. I am very anxious that other qualitative research continues to develop in the area of FAS because gaining a perspective of this disability from the individuals themselves illuminates understanding and presents a wealth of information and a host of further questions.

As I reflect over this project, and the whole issue of FAS, I continue to see it as part of a larger constellation of problems that result in alcohol's misuse. The focus of the residual model of social welfare has always been to adjust and rehabilitate individuals and families to the values and norms of society. But this is insufficient because alcohol consumption does not occur in a vacuum. From my perspective, society places such high values on alcohol because it's production contributes to financial gain, it serves as an ingredient in the denial and suppression of emotional pain, and, it is used to assist intimacy and reduce anxiety. Because of society's blatant misuse of alcohol, there must be courage to admit that there are some very fundamental problems with the structure of western society when such heavy reliance on a drug like alcohol is popularized. Society has been cautious about focusing negative attention on its number one drug of choice; a drug which is not only legal but

socially acceptable. Currently, the diagnosis of fetal alcohol syndrome or alcohol related effects, only puts a name to a problem society is not prepared to address (DeVries, 1990). Cultural, sociological, behavioural, public health and medical enlightenment are relevant to the prevention of FAS and related conditions (Stratton, Howe & Battaglia 1996). Campaigns to heighten public awareness of this disability are urgently needed as treatment begins when FAS and alcohol related effects is recognized as a major public health concern. The understanding of the effects of alcohol on the fetus unfortunately serve to demonstrate the necessity for government and social welfare to develop creative strategies around this issue.

Fetal alcohol syndrome and alcohol related effects is a disability which is 100% preventable but in order to realize prevention, the special needs of women must be considered. FAS does not occur in isolation. Fathers, friends, families and the community are also responsible. A conceptual framework which would encompass a broad spectrum of prevention measures include peer support, family and community support as critical factors in successful prevention programs. Understanding the socio-economic status of women is essential in order to prevent FAS/E. It is within the framework of patriarchal society which is oppressive towards women, that FAS/E occurs. FAS/E is not solely about women and drinking. It is about the greater context of alcohol's misuse within a society which inherently devalues women.

In order to prevent FAS/E in future generations, requires the involvement and commitment of government, communities and family. It requires further feminist research which targets the many levels of contributing factors. At all levels of prevention it must be noted that the approaches are long term. Effective prevention is community based with the community

identifying, assuming responsibility for and dealing with it by determining the strategies to use.

Currently there are no services for individuals who are FAS and have an IQ above 70.

The FAS diagnosis in itself does not necessarily qualify individuals for assistance, although one participant told me that she did receive a disability portion. Those who are mentally handicapped are eligible for a variety of assistance, including respite, assistance with community living, vocational training, additional medical services. These services are also applicable if the individual is living with family. However, those who have FAS or alcohol related effects and do not fit in the mentally handicap range, do not qualify for services. There is nothing specific to FAS. Programs need to be more tailored and very few people in the community understand what is involved. This was clearly evident, as Teresa who is handicapped, qualifies for multiple services, whereas the other participants do not. Dr. Sterling Clarren (1993) who runs the Fetal Risks Clinic in Seattle emphasizes that fetal alcohol affected adults or children, who have borderline to normal intelligence, are virtually unrecognized and hence unserved.

The cultural norm requires individuals to adapt and adjust to a fast paced, stimulating, cognitively distressing, abstract, industrial world. The realm of the FAS/E individual contradicts the cultural norm, and mirrors back to the world, it's rigidity and need to have individuals conform. Rathbun, (1993) emphasizes this:

Children and adults with FAS/E are the disowned opposite of the cultural norm. They careen between repetitiveness and distractibility,

psychic exhaustion and hyperactivity, rigidity and disorganization, embodying a host of behavioral paradoxes in the face of attempts to establish consistency, cooperation, and most of all, control. In our world which demands sophisticated ability to differentiate, prioritize, and produce with ever escalating speed, these children and adults are proverbial sticks in the mud. When they churn, attempting to keep pace with the systems around them, “their wheels spin and their carts don’t move” (Malbin, 1990, personal communication). They commit the ultimate cultural “sin” of being unable to “just get on with it”.....we can hear in the “problem” of FAS, the invitation to a change of pace and orientation to our values about learning, work, success, life and community....FAS/E people call forth models of another kind because they cannot use cultural structures as they are presently configured. (p.2)

Rathbun invites us to accompany individuals who have FAS/E, to where they are at, and to honour their positions and voices, and utilize what we hear to make adjustments in ourselves. It is only then, that our responses to these individuals will become more appropriate and empowering, thus enabling their future successes.

I am so impressed with the positive outlook each participant relayed to me, despite their frequent frustrations which occur in one way or another. Their cheerfulness and desire accommodate my questions truly enhanced my understanding of FAS and alcohol related effects. One of the participants told me at the end of our final interview together that I was the only one she has talked to regarding everything about FAS in her life. She found that talking really helped and allowed her to feel good about herself. This comment was truly rewarding for me, and is a demonstration of how research can in fact empower the participants. It is also an indication that their voices need to be heard.

I realized that despite the obstacles in front of the participants to achieve ordinary goals, their lives were true examples of perseverance. It was a honour to hear their stories and present their experiences so that understanding about FAS can continue to expand and prevention efforts increase. In retrospect, the participants in my study have truly been my teachers, and I am very grateful for all that they have taught me.

BIBLIOGRAPHY

- Abbott, A. A. (1995). "Substance Abuse and the Feminist Perspective." In, N. Van Den Bergh, (Ed). Feminist Practice in the 21st Century (pp.258-277). Washington, D.C: NASW Press.
- Abel, E.L., and Sokol, R.J. (1986). "Fetal Alcohol Syndrome is now the Leading Cause of Mental Retardation". Lancet, 2, 1222.
- Allen, K.R., and Baber, K.M. (1992). "Ethical and Epistemological Tensions in Applying a Postmodern Perspective to Feminist Research." Psychology of Women Quarterly, 14,1-15.
- Anderson, K. and Jack, D. "Learning to Listen: Interview Techniques and Analyses. In S.B. Gluck and D. Pate (Eds). Womens Words (pp.11-27). New York: Routledge.
- Aronson, J. (1985). "Family Care of the Elderly: Underlying Assumptions and Their Consequences." The Canadian Journal on Aging, 4, 2, 115-125.
- Blazek, S. and Wendel, S. (1995). "How Occupational Therapy can Help Children with FAS." Iceberg, 5, 4, 1-2.
- Bleicher, J. (1980). Contemporary Hermeneutics. London: Routledge and Kegan Paul.
- Bloss, G. (1994). "The Economic Cost of FAS." Alcohol, Health and Research World, 18, 1, 53-54.
- Blume, S. (1986). "Women and Alcohol: A Review." Journal of the American Medical Association, 256, 1467-1470.
- Brown, L.S. (1994). Subversive Dialogues: Theory in Feminist Therapy. New York: Basic Books.
- Braiker, H. (1984). "Therapeutic Issues in the Treatment of Alcoholic Women." In, S.C. Wilsnack and L.J. Beckman. Alcohol Problems in Women (pp.349-369). New York: The Guildford Press.

- Burman, S. (1992). "A Model for Women's Alcohol/Drug Treatment." Alcoholism Treatment Quarterly, 9, 2, 87-99.
- Canadian Centre on Substance Abuse, National Working Group on Policy (1994). "Fetal Alcohol Syndrome: An Issue of Child and Family Health."
- Cancian, F.M. (1992). "Feminist Science: Methodologies that Challenge Inequality." Gender and Society, 6, 4, 623-642.
- Clarren, S.K. and Smith, D.W. (1978). "The Fetal Alcohol Syndrome." New England Journal of Medicine, 298, 19, 1063-1067.
- Clemmons, P. (1985). "Reflections of Social Thought in Research on Women and Alcoholism." Journal of Drug Issues. (pp.73-80) In, D.Malbin "Why Bother to Identify These Kids: Identifying Fetal Alcohol Syndrome and Effects: Barriers and Potentials." Unpublished.
- Coffey, A. and Atkinson, P. (1996). Making Sense of Qualitative Data. Thousand Oaks: Sage.
- Coles, C., Platzman, K.A., Raskind-Hood, C.L., Brown, R.T., Falek, A., and Smith, I.E. (1997). "A Comparison of Children Affected by Prenatal Alcohol Exposure and Attention Deficit, Hyperactivity Disorder." Alcoholism: Clinical and Experimental Research, 2, 150-160.
- Conry, J., Fast, D.K., and Looch, C.A. (1997) "Youth in the Criminal Justice System: Identifying FAS and Other Alcohol-Related Neurodevelopmental Disabilities." B.C. Fetal Alcohol Syndrome Resource Society.
- Cooper, E. (1991). "Alcohol Use and Abuse by Women." CRS Report for Congress.
- Crespi, T.D. (1995). "Adult Children of Alcoholics: The Family Praxis." Family Therapy, 22, 2, 83-93.
- Day, N.L. and Richardson, G.A. (1991). "Prenatal Alcohol Exposure: A Continuum of Effects." Seminars in Perinatology, 15, 4, 271-279.

- Dedam, R., McFarlane, C., and Hennessy, K. (1993). "A Dangerous Lack of Understanding". The Canadian Nurse Magazine.
- DeVries, J. (1995). "Women with FAS/E Show Courage and Strength." F.A.S. Times. Fetal Alcohol Syndrome/Family Resource Institute. Lynwood Washington.
- DeVries, J. and Waller, A. "FAS Family Resource Institute Needs Assessments Validate Families Raising Children with FAS/E." F.A.S. Times. Fetal Alcohol Syndrome/Family Resource Institute Newsletter. Lynwood, Washington.
- Evensen, D. (1995). "Integrated Active Learning and the Child with FAS/E." Fasets Newsletter. Montana Fetal Alcohol Syndrome/Effects Program.
- FAS Information Service Providers Committee (1996). "Who's Asking? Measuring demand in B.C. for information about Fetal Alcohol Syndrome/Effects (FAS/E) and Neonatal Abstinence Syndrome (NAS). Unpublished.
- Finkelstein, N. (1990). "Changing needs of today's Addicted Women." In, R. Rhodes and A. Johnson. (1994) "Women and Alcoholism: A Psychosocial Approach." Affilia, 9, 2, 145-156.
- Friedler, G. (1994). "Effects on Future Generations of Paternal Exposure to Alcohol and Other Drugs." Alcohol Health and Research World, 12, 2, 126-129.
- Gelo, J. (1996). "The Value of an FAS Diagnosis." Iceberg, 6, 3, 1-6. Seattle, Washington.
- Greene, B. and Wilbee, S. (Chairpersons, Sub-committee on Health Issues). (1992). "Foetal Alcohol Syndrome: A Preventable Tragedy." Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors and Status of Women.
- Haraway, D. (1988). "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." Feminist Studies, 14, 3, 575-599.
- Health and Welfare Canada (1989). The Active Health Report on Alcohol, Tobacco and Marijuana. Ottawa: Minister of Supply and Services Canada.

- Hepworth, D.J. and Larson, J. (1986). Direct Sock Work Practice: Theory and Skills. Illinois: Dorsey.
- Hicks, C. (1988). Who Cares: Looking after People at Home. London: Virago Press.
- Jones, K.L., and Smith, D.W. (1973). "Recognition of the Fetal Alcohol Syndrome in Early Infancy." Lancet, 2, 999-1001.
- Jones, R. (1993). "Fetal Alcohol Syndrome and Effects: From Awareness to Action." Conference information compiled by the Washington Council on Crime and Delinquency. Seattle, Washington.
- Kail, R. (1979). The Development of Memory in Children. San Francisco: W.H. Freeman and Company.
- Kirby, S. and McKenna, K. (1989), Experience, Research, Social Change: Methods from the Margins. Ontario: Garamond.
- Kleinfeld, J. and Wescott, S. (1993). Fantastic Antone Succeeds: Experiences in Educating Children with Fetal Alcohol Syndrome. University of Alaska Press.
- Kuzel, A.J. (1992). "Sampling in Qualitative Inquiry." In B.F. Crabtree and W. Miller (Eds). Doing Qualitative Research pp.31-44. Newburk Park: Sage.
- Kvale, S. (1996). Interviews. Thousand Oaks: Sage.
- Kyvig, D.E. (Ed). (1985). "Sober Thoughts: Myths and Realities of National Prohibition after Fifty Years." In, Law, Alcohol and Order: Perspectives on National Prohibition. Connecticut: Greenwood Press.
- LaDue, R.A., Streissguth, A., and Randels, S.P. (1992). "Clinical Considerations Pertaining to Adolescents and Adults with Fetal Alcohol Syndrome." Perinatal Substance Abuse Research Findings and Clinical Implications. Baltimore: John Hopkins University Press.
- LaDue, R.A. (1990). "Doctors Urge Diagnosis". In, In The News, p.2-3. University of Washington Health Sciences Center.

- Layder, D. (1993). New Strategies in Social Research. Cambridge: Polity Press.
- Lefrancois, G.R. (1980). Of Children: An Introduction to Child Development (Third Edition). University of Alberta: Wadsworth Inc.
- Lincoln, S.Y. (1995). "Emerging Criteria for Quality in Qualitative and Interpretive Research." Qualitative Inquiry, 1, 3, 275-289. Thousand Oaks: Sage.
- Lord, J., Schnarr, A., and Hutchison, P. (1987). "The Voice of the People: Qualitative Research and the Needs of Consumers." Canadian Journal of Community Mental Health, 6, 2, 25-35.
- Luke, B. (1990). "Metabolic Basis of FAS." International Journal of Sertil, 35, 6, 333-337.
- Lundy, J. (1993). "Explicitness: The Unspoken Mandate of Feminist Social Work." Affilia, 8, 2, 184-199.
- MacDonald and Associates (1991). "The Prevention of Fetal Alcohol Syndromes in British Columbia." Ministry of Health.
- Malbin, D. (1990). "Why Bother to Identify These Kids: Identifying Fetal Alcohol Syndrome and Effects: Barriers and Potentials". Unpublished paper received from the Society for Special Needs Adopted Parents.
- Malbin, D. (1997). "Common Cycles of Individuals with Fetal Alcohol Syndrome/Fetal Alcohol Effects." Montana FAS/E Program.
- Marshall, C. and Rossman, G.B. (1995). Designing Qualitative Research. Thousand Oaks: Sage.
- Maxwell, J.A. (1996). Qualitative Research Design: An Interactive Approach. Thousand Oaks: Sage.
- McPhee, B. (1992). "Fetal Alcohol Syndrome-100% Preventable!" Healthsharing Magazine, (pp.46-49).

- Michaelis, E.K. and Michaelis, M.L. (1994). "Cellular and Molecular Bases of Alcohol's Teratogenic Effect." Reprinted from *Alcohol, Health and Research world*, 18, 1. In, *FAS/E Nation*, 1995, 3, 2. B.C. FAS Resource Society.
- Moon, S.M., Dillon, D.R. and Sprenkle, D.H. (1990). "Family Therapy and Qualitative Research." *Journal of Marital and Family Therapy*, 16, 4, 357-373.
- Moore, M.H. and Gerstein, D.R. (Eds). (1981). "Perspectives in Current Alcohol Policies." In, *Alcohol and Public Policy: Beyond the Shadow of Prohibition*. Washington: National Academy.
- Morse, J.M. (1994). "Designing Funded Qualitative Research." In, N.K. Denzin and Y.S. Lincoln (Eds). *Handbook of Qualitative Research* (pp.220-235). Thousand Oaks: Sage.
- Morse, J.M. and Field, P.A. (1995). *Qualitative Research Methods for Health Professionals*. Thousand Oaks: Sage.
- Nanson, J.L. and Hiscock, M. (1990). "Attention Deficits in Children Exposed to Alcohol Prenally." *Alcoholism: Clinical and Experimental Research*, 14, 5, 656-661.
- Neuman, W.L. (1994). *Social Research Methods*. Toronto: Allyn and Bacon.
- Olson, H.C., Burgess, D.M. and Streissguth, A. (1992). "Fetal Alcohol Syndrome and Fetal Alcohol Effects: A Lifespan View with Implications for Early Intervention." *Zero to Three/National Centre for Clinical Infant Programs*, 13, 1, 24-29.
- Opie, A. (1992). "Qualitative Research, Appropriation of the 'Other' and Empowerment." *Feminist Review*, 40, 32-51.
- Page, S. and Day, D. (1990). "Acceptance of the Mentally Ill in Canadian Society: Reality and Illusion." *Canadian Journal of Community Mental Health*, 9, 1, 51-59.
- Patton, J.Q. (1990). *Qualitative Research and Evaluation Methods* (2nd ed). Newbury Park: Sage.
- Plant, M. (1985). *Women, Drinking, and Pregnancy*. London: Tavistock.

- Rathbun, A. (1993). "Practical Approaches to Working and Living with FAS/E Children and Adults." Unpublished paper.
- Rathbun, A. (1993). "Alcohol/Drug Related Birth Defects (ARBD): An Overview of Symptoms and Strategies for Caregivers." FAS/Drug Effects Clinical Programs. Portland, Oregon.
- Rathbun, A. (1991) "Living and Working with Children and Adults with FAS/FAE." First International Conference on Education Children with FAS/FAE. University of Alaska, Fairbanks.
- Rhodes, R. and Johnson, A. (1994). "Women and Alcoholism: A Psychosocial Approach." Affilia, 9, 2, 145-156.
- Ritchie, J. and Spencer, L. (1994). In, A. Bynun and R.G. Burgess (Eds). Analyzing Qualitative Data (pp.173-194). New York: Routledge.
- Robinson, G.C., Conry, J.L. and Conry, R.F.(1987) "Clinical Profile and Prevalence of Fetal Alcohol Syndrome in an Isolated Community in British Columbia." Canadian Medical Association Journal, 137, 203-207.
- Sandelowski, M. (1994). "Notes on Transcription." Research in Nursing and Health, 17, 311-314.
- Sandelowski, M. (1995). "Qualitative Analysis: What it is and How to Begin." Research in Nursing and Health, 18, 371-375.
- Sandelowski, M. (1995). "Sample Size in Qualitative Research." Research in Nursing and Health, 18, 179-183.
- Sandmaier, M. (1980). The Invisible Alcoholics: Women and Alcohol in America. New York: McGraw-Hill.
- Schroedel, J.R. and Peretz, P. (1994). "A Gender Analysis of Policy Formation: The Case of Fetal Abuse." Journal of Health Politics, Policy and Law, 19, 2, 335-360.

- Single, E. (1995) "Canadian Profile-Alcohol, Tobacco and Other Drugs." The Canadian Centre on Substance Abuse and the Addiction Research Foundation.
- Sokol, R.J. and Clarren, S.K. (1989). "Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring." Alcoholism: Clinical and Experimental Research, 13, 4, 597-598.
- Stratton, K., Howe, C., and Battaglia, F. (1996). FAS: Diagnosis, Epidemiology, Prevention and Treatment. Washington: National Academy Press.
- Steinhasen, H.C., Willms, J. and Spohr, H. (1993). "Long Term Psychopathological and Cognitive Outcome of Children with Fetal Alcohol Syndrome." Journal of American Academy of Child and Adolescent Psychiatry, 32, 5, 990-994.
- Streissguth, A., LaDue, R.A. and Randels, S.P. (1988). "A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians." University of Washington, Department of Psychiatry and Behavioural Sciences.
- Streissguth, A., Clarren, S., and Jones, K.L. (1985) "Natural history of the fetal alcohol syndrome: A ten year follow up of eleven patients". Lancet, 2, 85-92.
- Streissguth, A., Barr, H.M., Kogan, J., and Bookstein, F. (1996). "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects." University of Washington School of Medicine. Department of Psychiatry and Behavioral Sciences.
- Streissguth, A. (1991). "Fetal Alcohol Syndrome and the Teratogenicity of Alcohol: Policy Implications." 8th World Congress of international Commission for the Prevention of Alcoholism and Drug Dependency.
- Streissguth, A., Aase, J.M., Clarren, S.K., Randels, S.P., LaDue, R.A. and Smith, D.F. (1991). "Fetal Alcohol Syndrome in Adolescents and Adults." Journal of the American Medical Association, 265, 15, 1961-1967.
- Streissguth, A. (1993). "Fetal Alcohol Syndrome and Effects: From Awareness to Action." Washington Council on Crime and Delinquency. Seattle, Washington.

- Streissguth, A. (1995). "Reflections on Fetal Alcohol Syndrome: A Conversation with Paul Lemoine". Iceberg, 4, 2.
- Streissguth, A., Moon-Jordon, A., and Clarren, S.K. (1995). "Alcoholism in Four Patient with Fetal Alcohol Syndrome: Recommendations for Treatment." Alcoholism Treatment Quarterly, 13, 2, 89-103. Haworth Press.
- Swigonski, M.E. (1990). "Feminist Standpoint Theory and Questions of Social Work Research." Affilia, Summer, 171-183.
- Vadheim, M. (1993). "Fetal Alcohol Syndrome and Effects: From Awareness to Action." Conference information compiled by Washington Council on Crime and Delinquency. Seattle, Washington.
- Van Den Bergh, N. (Ed). (1991). Feminist Perspectives on Addictions. New York: Springer.
- Van Den Bergh, N. (Ed). (1995). Feminist Practice in the 21st Century. Washington: NASW Press.
- Van Manen, M. (1990). Researching Lived Experience. Ontario: The Althouse Press.
- Watson, R. (1992). Alcohol and Neurobiology: Brain Development and Hormone Regulation. Arizona: CRC Press.
- Weiner, L., Morse, A.B., and Garrido, P. (1989). "FAS/FAE: Focusing Prevention on Women at Risk." International Journal of the Addictions, 24, 4, 385-395.
- West, J.R., Goodlett, C.R., and Brandt, J.P. (1990). "New Approaches to Research on the Long Term Consequences of Prenatal Exposure to Alcohol." Alcoholism: Clinical and Experimental Research, 14, 5, 684-689.
- Wilsnack, S.C. and Beckman, L.J. (Eds). (1984). Alcohol Problems in Women. New York: The Guildford Press.
- Winqvist, P. (1995). "Issues and Recommendations Related to Fetal Alcohol Syndrome Prevention, Awareness, Education, Care and Research in B.C." (Unpublished).

INTERVIEW GUIDE

1. Can you tell me what it is like living with Fetal Alcohol Syndrome/Effects?

Possible Probes:

What is difficult/ What is easy?

How did you do in school?

Can you tell me what it is like in terms of employment?

How do you manage financially?

What do you think your strengths are?

2. How did you find out you had Fetal Alcohol Syndrome/Effects?

Possible Probes:

How did it effect you when you found out?

What did you know about Fetal Alcohol then?

What do you know now?

3. Is there anything that you think professionals should know that would allow them to provide better support/help for adults with Fetal Alcohol Syndrome/Effects?

Possible Probes:

Do you feel you need any supports/help?

What are your sources of support?

A Day in the Life
by Andrew Age 22

Every day in my life brings me problems galore
If I don't stop and think what it is I'm looking for.
I stay up too late, and sleep all day long
Racking my brain to find what is really wrong.
Never finding the right answer, my frustration is real.
Doesn't anyone understand how I really feel?

When I try to control my compulsiveness
I just wind up in another mess.
The things I should do and never get done
It's so much easier to just go and have fun.
I know I must try to get a grip on myself.
I know I must try to get some help.
I'm trying to hold my own, but there's just so much to do.
Does anybody out there feel the way I do?

When I'm asked to do this, or to do that
I lie my way out of it or just blow my stack
I will be in trouble before long
Because the things I do all turn out wrong.
Will someone please help me be the person I want to be.
To fulfill my dreams realistically?

So to all you doctors, psychiatrists, psychologists and such
Please understand me, I'm trying so much
To help myself, each and every day;
But this FAE keeps getting in the way.
I have a brain though it is as confused as can be
About diseases they call FAS and FAE

How mothers can drink and think it's all right,
While later their babies will have to put up
a hell of a fight
To do the things that normally everybody can do-
Like tell right from wrong.
concentrate and even sleep, too.

So out to all of you readers this message does go:
Let your love for your children really show;
And no matter what they do don't give up the fight
Because in the long run you will
know that you have done what is right.

New Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects

*From: Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment
Institute of Medicine, Washington, DC*

Fetal Alcohol Syndrome

1. FAS with confirmed maternal alcohol exposure¹

- A. Confirmed maternal alcohol exposure¹
- B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g. flat upper lip, flattened philtrum and flat midface)
- C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportional low weight to height
- D. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:
 - decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

2. FAS without confirmed maternal alcohol exposure

B, C and D as above

3. Partial FAS with confirmed maternal alcohol exposure

- A. Confirmed maternal alcohol exposure¹
- B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

- C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportionate low weight to height
- D. Evidence of CNS neurodevelopmental abnormalities, as in:
 - decreased cranial size at birth
 - structural brain abnormalities (e.g. microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
- E. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention or judgment.

Alcohol Related Effects

Clinical conditions in which there is a history of maternal alcohol exposure^{1, 2} and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories, which may occur. If both diagnoses are present, then both diagnoses should be rendered:

4. Alcohol-related birth defects (ARBD)

List of congenital anomalies, including malformations and dysplasias

Cardiac	Atrial septal defects Ventricular septal defects	Aberrant great vessels Tetralogy of Fallot
Skeletal	Hypoplastic nails Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Clinodactyly Pectus excavatum and carinatum Klippel-Feil syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, hypoplastic kidneys, Horseshoe kidneys,	Ureteral duplications Hydronephrosis
Ocular	Strabismus Retinal vascular anomalies	Refractive problems secondary to small globes
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.	

5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of:

A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:

- decreased cranial size at birth
- structural brain abnormalities (e.g. microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

and/or

B. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition, specific deficits in mathematical skills; or problems in memory, attention or judgment.

¹ A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behaviour while drinking, or alcohol-related medical problems such as hepatic disease.

² As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

(From): Who's Asking? Measuring demand in B.C. for information about Fetal Alcohol Syndrome (FAS/E) and Neonatal Abstinence Syndrome (NAS)

Prepared for: The FAS Information Service Providers Committee

Member Agencies:

Alcohol and Drug Information and Referral Services

#202 - 3102 Main Street
Vancouver, B.C. V5T 3G7

B.C. Prevention Resource Centre

#211 - 96 East Broadway
Vancouver, B.C. V5T 1V6
Toll-free: 1-800-663-1880
Phone: (604) 874-8452
Fax: (604) 874-9348
E-mail: bcprc_info@mindlink.bc.ca

The Resource Centre provides a toll-free information service for residents of the province seeking information about prevention contacts, organizations, programs, materials and research in the area of substance misuse. The Centre also has a collection of prevention resource materials for on-site use. Included in this collection are a variety of FAS and NAS resource materials.

FAS/E Provincial Prevention Coordinator

Sunny Hill Health Centre for Children
3644 Slocan Street
Vancouver, B.C. V5M 3E8
Phone: (604) 434-1331, local 230
Fax: (604) 431-7395 or (604) 436-1743
E-mail: clegge@sunnyhill.bc.ca

In order to provide a coordinated approach to dealing with fetal alcohol syndrome (FAS), Alcohol and Drug Services funds the position of Provincial FAS Prevention Coordinator. The goal of this position is to reduce developmental delays, birth defects and death due to prenatal alcohol and other drug misuse. The coordinator provides an information and referral service for the public on how to access information, resources, expertise and services related to FAS/E. The coordinator also helps with networking among health, education, justice and social service agencies.

FAS/E Support Network

14326 Currie Drive
Surrey, B.C. V3R 8A4
Phone: (604) 589-1854
Fax: (604) 589-8438
E-mail: fasnet@istar.ca

The FAS/E Support Network provides information, support, consultation and advocacy services for individuals, families, professionals and the broader community around prevention, intervention and treatment issues pertaining to alcohol related birth defects (FAS/E) caused by alcohol use during pregnancy. Included in the services are the WARMLINE, FAS support groups and publications, such as About FAS/E, Layman's Guide to FAS and FAS NET Assessment tools.

FAS/FAE Information Service

Canadian Centre on Substance Abuse
#300 - 75 Albert Street
Ottawa, Ont. K1P 5E7
Toll-free: 1-800-559-4514
Phone: (613) 235-4048
Fax: (613) 235-8101

Inclusion Resource Network (formerly Integration Support Line)

#100 - 550 West 6th Avenue
 Vancouver, B.C. V5Z 4P2
 Toll-free: 1-800-876-8542
 Phone: (604) 871-1864
 Fax: (604) 871-2296
 E-mail: khorne@bctf.bc.ca or jblenkinsop@bctf.bc.ca
 Homepage: <http://www.bctf.bc.ca/bctf>

This joint project of the Ministry of Education and the B.C. Teachers' Federation provides information and consultation to teachers, school personnel, and parents of children with special needs including FAS.

Regional Resource Centre Health Canada

Medical Services Branch, Pacific Region
 #304 - 1155 West Pender Street
 Vancouver, B.C. V6E 4J4
 Phone: (604) 666-2416
 Fax: (604) 666-2689

Resources are available to First Nations parents, groups, and educators. There are videos, kits, manuals, displays and brochures dealing with FAS and the effects of alcohol on pregnancy. We provide distance loan services support to front line workers in and for First Nations communities in B.C.

Society of Special Needs Adoptive Parents (SNAP)

#1150 - 409 Granville Street
 Vancouver, B.C. V6C 1T2
 Toll-free: 1-800-663-7627
 Phone: (604) 687-3114
 Fax: (604) 687-3364
 E-mail: 74757.3473@compuserve.com

SNAP is a provincial organization dedicated to assisting special needs adoptive families through mutual support, information sharing and advocacy. SNAP provides support groups and one-to-one contact resource parents throughout B.C. The Society operates a toll-free (in B.C.) telephone contact line and publishes a quarterly newsletter, as well as, publishing booklets such as "Parenting Children Affected by FAS: A Guide for Daily Living". SNAP also maintains a large resource library of books, periodicals, reports, audio tapes and videos.

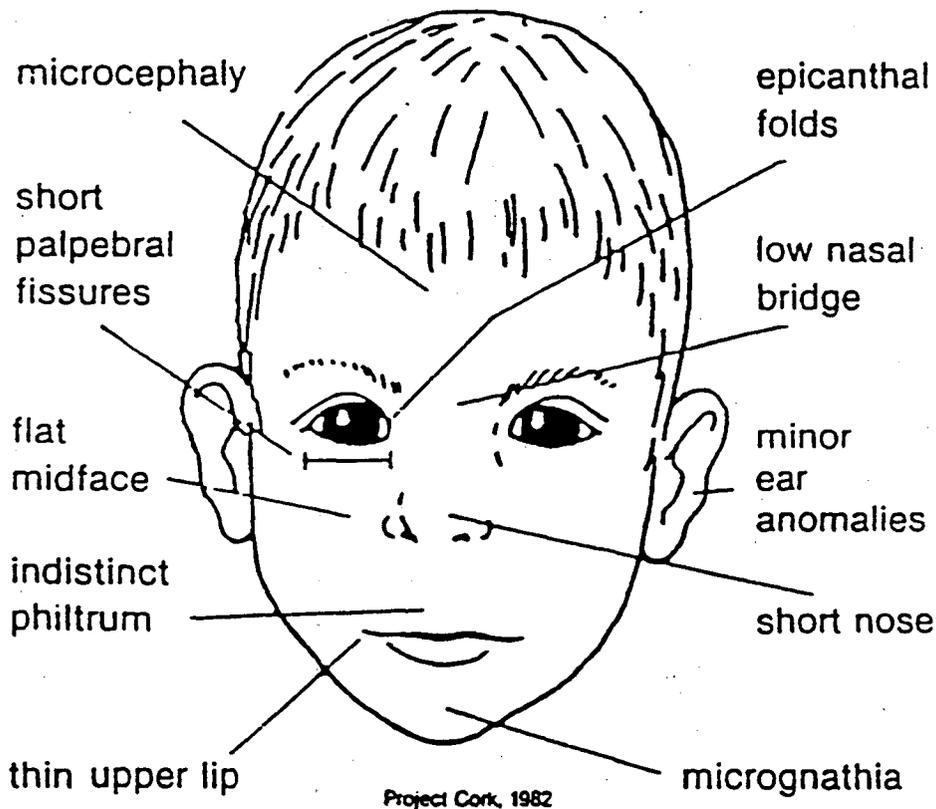
YWCA Crabtree Corner FAS/NAS Prevention Project

101 East Cordova Street
 Vancouver, B.C. V6A 1K7
 Phone: (604) 689-2808
 Fax: (604) 689-5463

YWCA Crabtree Corner FAS/NAS Prevention Project offers FAS/NAS educational workshops, a resource lending library, a peer support group for moms with children with FAS/NAS and information and crisis counselling. Crabtree Corner has published posters and pamphlets, as well as three guides:

- FAS/FAE and NAS Community Prevention Guide
- Guide for Parents, Caregivers and Others Caring for Children with FAS/FAE and NAS
- FAS/FAE and NAS Guide to Resources

FACIES IN FETAL ALCOHOL SYNDROME



Expanded "Special Interest" Section

Dedicated to Drug Abuse, Chemical
Dependency and Related Topics

Compiled by KCMS Committee on Alcohol, Drug and Tobacco Abuse

Source: Streissguth, A. (1990b) Fetal Alcohol Syndrome and the Teratogenicity of Alcohol: Policy Implications, The Bulletin, King County Medical Society, 69 (5) cover.