

GUIDES WITHIN THE CIRCLE:  
ABORIGINAL COUNSELLORS' EXPERIENCES WITH  
ABORIGINAL FAMILIES AFFECTED BY FETAL ALCOHOL SYNDROME

by

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## ABSTRACT

This research explores the experiences of six Aboriginal counsellors who provide services to Aboriginal families affected by Fetal Alcohol Syndrome. The focus of this research is on the experience and skill which First Nations counsellors employ with Aboriginal families affected by the disease. As well, literature on Fetal Alcohol Syndrome and counsellors' prevention and intervention strategies are explored. The current F.A.S. literature and Canadian Aboriginal history explored in the literature review roots the counsellors' present day experiences in the "Constructions" chapter.

Within this qualitative research project, transcribed in-depth interviews of six Aboriginal counsellors' experiential knowledge were explored through the use of narrative analysis techniques. Analysis of the data revealed various themes. The themes indicated that Aboriginal counsellors' concerns regarding F.A.S. included: Aboriginal identity (for themselves and their clients); counselling work issues; as well as acknowledgement of the strengths and weaknesses in agencies and professional practice that currently influence Aboriginal families affected by F.A.S. There was also a theme regarding emotions and feelings running throughout all the interviews. The themes reveal that the experience and perspective of Aboriginal counsellors is unique and valuable. The thesis concludes with recommendations about treatment offered to families affected by Fetal Alcohol Syndrome.

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## INTRODUCTION

The purpose of this research study is to explore the experiences of First Nations counsellors who provide services to First Nations families affected by Fetal Alcohol Syndrome (F.A.S.). Connecting voice to collective memory and individual experience is perhaps the most powerful way to reveal the working practice of First Nations counsellors. Indeed, my own experience as a mixed-heritage First Nations woman includes the exploration of my own voice which has been veiled by a mixture of societal, academic, and professional principles and standards. Any analysis of my own practice as a social worker however, is not separate from the identity that I carry through heritage and ancestry, through culture and community. I believe a strong focus for the amelioration of health conditions for First Nations people will come primarily through a reclamation and articulation of our own knowledge, as it is this memory and experience of living as First Nations that provides the basis for all other experiences in the world, and thus, the skill with which we practice our craft as counsellors.

Fetal Alcohol Syndrome (F.A.S.) was a term developed by K. L. Jones and D. W. Smith in 1973 to describe a disease believed to be caused by maternal alcohol consumption during pregnancy. F.A.S. is a medical diagnosis and children affected by the disease have symptoms which include slow growth and development, craniofacial and cardiovascular abnormalities, and retarded psychological development (Jones & Smith, 1973). These effects noted above will vary in intensity in every child.

To date, there is no clear connection between the amount of alcohol consumed and causation of F.A.S. in an unborn child. But, the disease has had a profound impact on our society, as health literature often describes F.A.S. as being one of the leading causes of mental retardation in North America (AADAC, 1993; Graham-Clay, 1983). This is only one known

outcome of F.A.S. Other psychological, social and cultural impacts are just beginning to be understood and much remains unknown about the impact this disease may yet have intergenerationally.

Through this research, I heard from the practitioners in the First Nations community that F.A.S. is a particularly terrible disease because it is one result linked to hundreds of years of racism. They shared their belief that oppression has forced First Nations to medicate themselves through alcohol and drugs from the pain of their experience as a politically disempowered people. F.A.S. is a unique problem for Native Nations because this disease deeply penetrates into the heart of our communities, as it effects our children, their individual sense of self-esteem and pride, and therefore, our belief in ourselves as First Nations. This disease has the potential to change the very cultures of Aboriginal Nations because the origin of F.A.S. in First Nations communities lies fundamentally in connection to colonisation which continues to be practised today.

In many ways, this disease furthers the legally sanctioned practices associated with genocide meted out throughout the centuries upon Native Nations. And ultimately, the blame and guilt for alcoholism and our children affected by F.A.S. are placed upon our own people, and more precisely, upon the shoulders of First Nations women. F.A.S. ravages not one Aboriginal person, or family, or community, but the very existence of our future generations. Thus, the politics of First Nations health and how we prevent and treat F.A.S. is connected to our survival as distinct cultural communities.

F.A.S. is a devastating problem that causes irreversible damage, although for many this lifelong condition is manageable. Important to understanding F.A.S. is that this disease is preventable and because of its connection in First Nations communities to distinct systemic

factors, this disease cannot be treated strictly as an issue of addiction. Therefore, treatment programs for First Nations communities affected by F.A.S. must be developed specifically within a particular framework that acknowledges cultural values and the connections between therapeutic interaction and social action. As a counsellor, I know that learning how to offer help to stop this disease means I must listen to the voices of those First Nations counsellors who work with families affected by F.A.S. in the First Nations community. In an effort to develop effective prevention and treatment strategies to incur social change, I feel it is extremely important to document our voices in order for us all to participate in the solutions.

F.A.S. is spreading rapidly despite being addressed by traditional medical services, including; medical health professionals and medicine, as well as crisis-oriented agencies focused on abuse and addiction issues in the First Nations community (Four Worlds Development Project, 1985). Research has shown that these current intervention services do not provide long-term answers to First Nations intergenerational concerns and issues such as alcoholism (Falconer & Swift, 1983). Thus, it can be argued that these conventional treatment routes are not of particular help to those First Nations families affected by F.A.S. Therefore, programs that challenge the specific issue of F.A.S. within the First Nations community must now be developed in order to counteract the spread of this disease. A radical redefinition of practice in this counselling area can and will come from the strong personal commitment and dedication of First Nation counsellors themselves, who hold unique counselling perspectives, skills and tools that can challenge the spread of this disease.

Fetal Alcohol Syndrome is not an issue connected solely to First Nations communities, but the knowledge, service and practices that First Nations counsellors offer to their community are of vital importance in the prevention and treatment of this disease. What experiences do

Native practitioners have with their clients? What tools do they use and what gifts do they bring to their work? Social work practice, having been defined and redefined through patriarchal convention, is a ripe area "...for testing, revision/testing..." (Stolar, 1994) by First Nations practitioners. A good step towards offering effective practice efforts focused on F.A.S. will be taken by documenting First Nations counsellors' knowledge and practices.

Aboriginal counsellors must provide service at the interpersonal level, but as peoples fighting to realise social and political empowerment, we must also be engaged in revolutionary movement at a social/political level stating our right to self-determination for each Native Nation. For Aboriginal counsellors this inevitably means struggling to clearly determine and define how we intend to integrate Aboriginal-defined health practices focused on F.A.S. within the more general struggle for legitimacy as practitioners with unique service delivery insight within the Canadian social services and health systems. So, my struggle and part of the responsibility that I have to my community as a First Nations woman and as a social worker is to encourage the voice of other First Nations counsellors in research and literature.

The experiences of the Aboriginal counsellors that I meet are integral to the growing competence and awareness within the total social services community. Without the expression of our lives as First Nations people we are silenced and exist on the edge of acceptability. Yet, as individuals, as well as professionals, we have valuable knowledge, opinions and practices to share. In many ways today, Native Nations find their way back to the circle of their communities, spirituality and heritage. It is powerful work to rediscover our skills and beliefs that have been stripped away and then hidden for so long from our people. At the very core of my being, through all life learning, I do not forget the history of my family which seems to

resonate deep within my soul. It has been within long before I knew the ways to practice social work.

A personal path of healing, rediscovery, pride and recovery from personal trauma are integral to professional practice for many counsellors from the First Nations community. The “Red Road”, or the path of healing, is described as the journey through which the First Nations person finds their own connections to tradition and the “old ways” (Osenntion & Skonaganleh:ra, 1989), however individually defined. Ultimately, this research attempts to discover how the personal histories of six First Nations counsellors help to shape their own professional practice.

This study will include five chapters. The first chapter will review literature that discusses F.A.S. and some of the history and issues surrounding the disease, as well as how First Nations counsellors and conventional treatment programs are working for people affected by F.A.S. The second chapter looks at the historical context behind First Nations connection to F.A.S. In particular, I would like to immediately acknowledge the distinct lack of information in the literature on First Nations counsellors and how they bring their own specific tools, knowledge and professional skill to F.A.S. counselling, prevention and treatment programs.

In this thesis, chapter three will focus on the method used to help uncover those voices of the counsellors who participated in the interviews to explore their experience with individuals affected by Fetal Alcohol Syndrome in the First Nations community. In chapter four, the interview “constructions” will be presented and discussed. And, finally in chapter five the conclusions and recommendations of the study will be noted.

This research is done with the intent of creating awareness, as well as to provide insight to the reader that may lead to advocacy and further research in the field. Please note that the

words “Aboriginal”, “First Nations” and “Native Nations” appear throughout this essay. I chose to use these words to describe Canadian Aboriginal peoples without attributing any discriminatory political distinction between status, non-status, and Metis peoples. As one participant pointed out, it is important to recognise that our people have had vastly differing life experiences dependent solely on government-defined identity. I hope that this research may be a part of the reclamation of voice so important to the healing and growth of the First Nations community.

## CHAPTER ONE

### AN F.A.S. OUTLINE FROM CURRENT LITERATURE

#### Description of F.A.S.

Fetal Alcohol Syndrome (F.A.S.) is a diagnosis given to children who display a number of physical, psychological and behavioural characteristics known to be caused by maternal alcohol consumption during pregnancy (Jones & Smith, 1973). Children must display a certain pattern of these characteristics in order to be diagnosed with F.A.S. The criteria used to diagnose F.A.S., along with knowledge that the mother has ingested alcohol during pregnancy include craniofacial abnormalities, growth retardation and central nervous system dysfunction (CNS) (AADAC, 1993). F.A.S is known to be one of the leading causes of mental retardation in the world (Abel & Sokol, 1986) and yet it is a disease that is 100% preventable.

Alcohol is a teratogen, a product that can affect fetal growth (Bray & Anderson, 1989; Carney & Chermak, 1991; Looock, 1991). It is believed that when this product, or alcohol ethanol, passes through the placenta it may damage the developing fetus (Clarren 1981; Graham-Clay, 1983). The Saskatchewan Institute on the Prevention of Handicaps (1992) notes:

An unborn baby is nourished through the mother's placenta. When the mother drinks, alcohol passes freely through the placenta to the unborn baby, or fetus. The fetus's liver does not work as well as the mother's liver in breaking down the alcohol. Alcohol stays in the unborn baby's body longer. Both alcohol and it's major breakdown product, acetaldehyde, cross the placenta and can damage the developing fetus (p. 1).

But, it is not known exactly how alcohol causes Fetal Alcohol Syndrome, or how it is connected to the causation of any other birth defects. As well, it is noted by Clarren et al. (1978) that F.A.S. is only one outcome of alcohol altering the fetus. There can be a wide variability of damage to a fetus and this may be due to a variety of other factors affecting a pregnancy.

Warner and Rosett (1975) noted that information about the damaging effects of alcohol consumption to the fetus has been known to exist since the time of the ancient Romans and Greeks. Most of the recent studies on F.A.S. have been done on animals. It was not until 1973 that the Americans Jones and Smith with their colleagues published their breakthrough research describing the clinical symptoms of eight different children who were born to mothers who drank alcohol while pregnant. This group of researchers named this clinical pattern of characteristics, Fetal Alcohol Syndrome.

Alcohol Related Birth Defects (ARBD) are the source of a number of difficulties for affected children, but it is important to remember that F.A.S. rests at only one end of the continuum of outcomes for mothers who drink alcohol while pregnant (Robinson, Conry & Conry, 1987). A fetus that has not been affected as severely by alcohol consumption and who shows only one or two of the symptoms used to diagnose F.A.S., may be diagnosed with Fetal Alcohol Effects (FAE). On the continuum, alcohol ingested during pregnancy may also cause stillbirth, miscarriage, or may produce no effect to the fetus at all (Robinson, Conry & Conry, 1987).

There is also currently little known about the quantity of alcohol it takes to damage a fetus and it is not known if there is a safe level of alcohol that may be ingested by a mother during pregnancy. Friedler's 1987/88 research supports the idea that "prolonged paternal exposure to ethanol also can result in behavioural effects in young rodent offspring" (p. 126). Therefore, F.A.S. is not necessarily the outcome of an alcoholic, or substance-abusing mother, in fact, it may be that a moderate amount of alcohol during pregnancy, possibly even through paternal exposure may also cause alcohol-related birth defects (Abel, 1992; Hanson, Streissguth



& Smith, 1978). Currently, research leads many professionals, doctors and community activists to promote abstinence during pregnancy to avoid any potential damage to the fetus.

Some of the other elements involved in the development of F.A.S. and the intensity of its effects may include: the amount of alcohol consumed by the mother during pregnancy; when she drank (stage of fetal development) and how often; overall health, including nutrition and physical/mental health; as well as age and lifestyle of the mother (AADAC, 1993; MacPhee 1992). Other genetic disorders may influence the fetus and the intensity of the disorder (AADAC, 1993). Moreover, systemic/environmental problems including poverty, economics, as well as social and cultural issues may all contribute to alcohol ingestion during pregnancy (AADAC, 1993; MacPhee, 1992). And finally, an examination of bias in F.A.S. research and the interpretation of research outcomes may be a factor in who and how often F.A.S. is diagnosed (Loock, 1990).

### Diagnosis

Once a child has exhibited abnormalities in each of the noted areas, growth, central nervous system and face, a child may be diagnosed with Fetal Alcohol Syndrome (AADAC, 1993; Clarren, 1981). This diagnosis is dependent on the level of severity of each symptom. Also, if it is possible, confirmation of alcohol consumption during pregnancy should be acquired in order to make a specific diagnosis of F.A.S. (AADAC, 1993). Clarren (1981) discovered that the list of characteristic anomalies found in people diagnosed with F.A.S. is growing constantly and so it is likely that the number of people diagnosed with F.A.S. may expand as the definition of the diagnosis expands.

There are many difficulties in establishing a diagnosis of Fetal Alcohol Syndrome. Despite the characteristics documented in the literature which lead to the diagnosis of F.A.S., the

Syndrome is not clearly recognisable. There is no single test for F.A.S., and therefore, apparent symptoms may be labelled as other alcohol-related birth defects (ARBD), or may even be diagnosed as another disorder entirely (Weiner & Morse, 1991). As well, recognition of craniofacial abnormalities can be subjective measurements as facial characteristics of children from different ethnicities may not be represented in the specific measurements used to diagnose F.A.S. (Robinson, Conry & Conry, 1987).

Often the symptoms of the disease may vary with age and a child who was not diagnosed at birth will likely not be diagnosed later in childhood (Rinkel, 1992). It is particularly difficult to diagnose and offer appropriate services to youth and adults affected by F.A.S. (MacPhee, 1992, March). Behavioural problems are exhibited in many disorders and by many who are not fetal alcohol affected. This consideration alone makes the disease difficult to treat if diagnosis is not done at birth.

Maternal alcohol use is difficult to measure and this information may not be available, particularly for those children who have been adopted or placed in foster care (Weiner & Morse, 1991). A mother may be involved in other drug use which may cloud recognition of the specific symptoms of F.A.S. Further, women who have children with F.A.S. are often stereotyped, particularly if they are women of colour, or if they work and/or live on the streets (Rinkel, 1992). Their children may be diagnosed and/or apprehended without proper consultation about their drug history, or without consideration of their personal history (MacPhee, 1992).

Finally, F.A.S. is still seen by some professionals as a fairly new syndrome and a child may not be diagnosed with F.A.S. because of lack of professional knowledge, denial and personal feelings about the disease (Canada, 1992, June; Funkhouser & Denniston, 1985). Professionals may not be fully cognisant about the research in this area, which may also lead to

non-diagnosis and/or over-diagnosis in some ethnic groups (Funkhouser & Denniston, 1985).

The determining factors that lead to a diagnosis of F.A.E., F.A.S., or another alcohol related birth disorder (ARBD) are very obscure and misdiagnosis of the symptoms is possible (AADAC, 1993). The social environment may also limit resources available to professionals to further research this syndrome, leading to misunderstandings about F.A.S. that make prevention difficult, diagnosis controversial and treatment confusing (Canadian Centre on Substance Abuse, 1992).

### Visibility/Invisibility

Children who are diagnosed with Fetal Alcohol Syndrome may have a vastly different life experience than those who are never diagnosed. Depending on diagnosis, a child becomes visible or invisible to her/his peers, family, community and helping professionals with a syndrome that requires certain attention and special care. F.A.S. is not well-known to the general public, nor even the professional community and therefore there is much controversy over labelling a child with this Syndrome. Labelling may allow one child to receive proper services which positively reinforces their successful life experiences, but another child may be stigmatised by a label which frustrates their attempts to succeed in life.

Early diagnosis is promoted by many professionals as crucial to assuring proper services to children with Fetal Alcohol Syndrome (Giunta & Streissguth, 1988). Later in their lives, youth and adults who live with this Syndrome may experience a variety of medical, educational and employment needs which can only be handled by multiple agencies and resources (Loock, 1990). Proper diagnosis may help to organise these required services and help to defer the costs of the services incurred, depending on an individual's needs and their medical insurance coverage. For instance, if a child is diagnosed with F.A.S. while in foster care certain services

will be paid for them through the government, but if a child is adopted their caretaker must pay extra medical expenses.

When a child is diagnosed a number of strategies can be developed by caretakers that can help the child cope with their behaviours, learning disabilities, medical problems and social interactions. As Rathbun and Malbin (1992) note:

Without identification of the organic symptoms complicating the child's developmental progress, the child experiences difficulty and becomes seen as "difficult" rather than handicapped (p.1).

Labelling a child with F.A.S. may indeed lead the individual and their family to better strategize for future hurdles. And, if a child is at risk for abuse or neglect in the environment in which they live early diagnosis can help identify services for the family to help them cope with the F.A.S. and/or ameliorate their general living situation.

Labelling a child with F.A.S. may also bring that child and family the guilt, pressure and stress associated with a disease that is highly condemned by the general public. As well, diagnosis suggests a large economic investment may have to be made in the child depending on particular disabilities and treatment needs. It may be that this label causes a child to walk with a stigma that increases difficulty in life negating any good that management strategies and interventions are designed to initiate. Difficult behaviour and social problems may be reinforced by the label, particularly if interventions are not appropriate for a child's unique needs. A misdiagnosis of F.A.S. may also have social and emotional repercussions that burden a child and family unnecessarily (AADAC, 1993).

Ann P. Streissguth (1992) outlines ten misconceptions about F.A.S. She includes the myth that a child will necessarily be mentally retarded if they are diagnosed with F.A.S., or that behaviour problems associated with F.A.S. are the sole result of poor parenting or a bad

environment (Streissguth, 1992). These misconceptions may further lower a child's self-esteem and lead that person to an adulthood where they continue to practice self-defeating behaviour because of the F.A.S. label attached to them.

Familial and environmental factors should be considered when a child is diagnosed with F.A.S. For instance, a child's living environment and support available in the child's school system for their specific pattern of disabilities and behavioural problems will play a huge part in provision of support after diagnosis. The most encouraging strategies for these children and their families must be specifically oriented to their own concerns and needs. The availability of a single case manager who will guide the family to find the variety of services that are needed for the child with F.A.S. (Giunta & Streissguth, 1988) can play an important part in effectively providing service to the family.

Finally, as Julie Conry discussed at an F.A.S. symposium held in Vancouver, B.C. (Canada, 1992, September/October), if a child is not diagnosed with F.A.S. then what will that child be labelled? Where will the support and intervention come from if the person grows into their poor social skills, impulsivity and poor boundary setting without the knowledge that there is help for their problems (Canada, 1992, September/October). These issues are very complex and are still debated in the social services and medical fields by service providers. It must be mentioned again though, that the vast majority of service providers suggest that diagnosis positively influences an individual's life by helping to bring professional awareness and care to families affected by this disease (Burgess & Streissguth, 1992; Giunta & Streissguth, 1988; MacPhee, 1992; YWCA, 1993).

### Prevalence of F.A.S.

Statistics on the prevalence of Fetal Alcohol Syndrome vary greatly. As researchers have used a variety of ways in which they have calculated the rate in sample populations, the overall population rate has also varied greatly in the literature. For instance, the Standing Committee report to the House of Commons suggests that over-diagnosis has occurred in the First Nations community, while F.A.S. has been underestimated in the rest of the Canadian population (Canada, 1992, December).

There are a variety of reasons for the discrepancy in estimated F.A.S. prevalence rates. For example, there have been more studies on F.A.S. in the Aboriginal community than in any other sub-group (May & Hymbaugh, 1983; Robinson, Armstrong, Moczuk, Loock, 1992; Robinson, Conry & Conry, 1987). Abel (1990) suggests that there may be genetic or racial risk factors involved in the occurrence of F.A.S. However, Burgess and Streissguth (1992) found that although F.A.S. may occur more frequently in some population groups, it does not exist solely within any racial or ethnic group. And May (1991) notes that social drinking patterns and norms may play a large role in the reported F.A.S. incidence level.

There are many other factors involved that have altered the currently reported rates of F.A.S. incidence levels. These include systemic factors preventing women from accessing proper medical care, denial of F.A.S. in various sub-groups by professionals, all the difficulties associated with diagnosing F.A.S., and those children who are misdiagnosed or who die at birth (Canadian Centre on Substance Abuse, 1992; Funkhouser & Denniston, 1985; MacPhee, 1992). Loock (1990) writes that the incidence rate reported to the B.C. registry of F.A.S. births is low "due to the registry's voluntary reporting system, maternal denial of drinking, poor history taking, and the lack of knowledge of FAS/FAE among health professionals" (p. 2). As well, most

population estimates are considered to be very moderate because of the difficulty in diagnosing children and/or finding correct historical information about the amount of alcohol a woman drank while pregnant (Harwood & Napolitano, 1985).

Abel and Sokol (1991) found the incidence rate of F.A.S. in the Western world to be 1 case in 3000 people. This rate was dependent on the ethnic and socio-economic status of the population being studied and different averages were found for the Black, Caucasian and First Nations populations (AADAC, 1993). In Canada, there is no current incidence rate known. Health and Welfare Canada have suggested that the F.A.S. rate is approximately 1 to 2 cases per 1000 children, but this estimate is based on out-of-date American F.A.S. incidence rates (Canada, 1992, June). These numbers also do not show the degree to which F.A.S. is represented in specific sub-group populations and whether or not this representation is skewing the overall data.

At this time, there is an increasing awareness in the social services and health fields of the dangerously growing level of birth defects, developmental and learning disabilities, and retardation of First Nations children in the Yukon and British Columbia due to alcohol ingested during pregnancy (Asante & Nelms-Matzke, 1985; Burgess & Streissguth, 1992; Streissguth, Aase, Clarren, Randels, LaDue & Smith, 1991). As May and Hymbaugh (1989) note:

While FAS and FAE have been shown to be no more prevalent among some tribes than among the general populations of the United States, Sweden and France, particular tribes have very high rates (p. 509).

Much of the collected data on rates seems to indicate high rates of F.A.S. in both Canadian and American First Nations populations.

In British Columbia, Betty MacPhee (1992) notes that "there is no central collection system or centralised information on children, let alone for FAS/NAS incidence information" (p. 377). But, it was estimated in a study entitled, "Report on the Survey of Children with Chronic

Handicaps and Fetal Alcohol Syndrome in the Yukon and Northwest British Columbia” (Asante & Nelms-Matzke, 1985) that F.A.S. or F.A.E. was identified in 59% of pregnancies and 30% of the 600 children in the study group, while 67% of those children were of First Nations origin (p. 37). And, in one isolated community in British Columbia, 14 out of 123 children were diagnosed with F.A.S., which translated into an F.A.S./F.A.E. rate of 190 out of 1000 children in the 0 to 18 age group (Asante, 1981; Robinson, Conry & Conry, 1987), which is dramatically higher than the estimate for the general Canadian population reported by the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women in June 1992.

Fetal Alcohol Syndrome could conceivably be incredibly damaging to the First Nations community if the current estimates in the Canadian Aboriginal population are true. There is no way to predict accurately what the correct current F.A.S. rate is for Canada, or even for those provinces that have been the focus of current studies, because there has been so little overall research on Fetal Alcohol Syndrome rates. Accurate rates are not likely to be available for a while, as this particular kind of investigation is complex and expensive (AADAC, 1993). It is estimated that “F.A.S. and F.A.E. may be more common than Downs syndrome (approximately 1.7/1,000) and Spina Bifida (approximately 1.4/1,000) combined” (Loock, 1990; p. 3).

Prevalence and incidence rates aside, what is established by the facts and figures available is that many children are facing lives of disabilities because of F.A.S. To understand what this disease really looks like it is extremely important to recognise surrounding factors influencing the disease, which I will turn to in the next section.



Social and Gender Issues: Women and F.A.S.

F.A.S. is a complex problem, but what the literature does make clear is that those individuals who are at highest risk for having to manage this disease are women living in poverty. It was stated in general discussion at the Vancouver symposium on F.A.S. that the disease "...is not a woman's issue but rather a societal issue..." (Canada, 1992, September/October; p. 41). At the very heart of this crisis, when levels of F.A.S. are continuing to rise society needs to question not why women are causing this disease, but why women are more likely to be in this situation and do not have access to adequate resources to help them understand and manage the disease.

Professionals and communities should also question who has the responsibility to provide women with information regarding health care, including drinking alcohol while pregnant. As Betty MacPhee (1992, March) has stated, "although women from poorer communities often do not access the health system and therefore do not receive any FAS education, women from more affluent communities do not receive the information either" (p. 5). Not only is information about F.A.S. not readily available to women, but research in this area, as well as services and programs for women and children affected by alcohol and drugs, are also sadly lacking in our communities.

Ultimately, how a society takes steps to prevent and treat a particular disease reveals the moral and ethical responsibility we individually feel to support our community members who are affected. As noted above, there are many myths regarding poor women whose children are affected by F.A.S. Indeed, Looock was cited in Ryder's (1991) article as saying, "Teenage mothers and career women who have delayed childbearing and are used to a glass of wine at dinner are also at high risk" (p. 3). Therefore, any woman is at risk for having a child affected by

F.A.S. if she does not have adequate information to make informed decisions about her pregnancy.

The literature documents higher risk of F.A.S. births within a particular social and environmental context. At the Vancouver Symposium on F.A.S. and F.A.E it was noted that a higher incidence of F.A.S. pregnancies was found in remote, rural and First Nations communities; in poor, inner-city communities; and among women with alcohol/drug problems, as well as women in lower socio-economic groups (Canada, 1992, September/October). It is extremely important to note that whether or not women have information regarding maternal alcohol consumption higher-risk environments are perpetuated by sexism, racism, poverty and other systemic oppressions. This societal condition then results in inadequate F.A.S. resources and services, as well as lack of government-sponsored and/or private source monies for research, education and prevention efforts regarding F.A.S. As Anne George writes in the YWCA FAS/FAE and NAS prevention series (1993):

Women face discrimination at work, in education, in social and health services, in sports, at banks and elsewhere. Some women experience abuse (physical, sexual and mental) and some live in poverty.

Discrimination, abuse, poverty all lead to shame, guilt, embarrassment, and low self-esteem, which in turn lead to a continuation of a cycle and a real challenge to reversing substance dependency (p. 5)

Unhealthy environments may lead to adaptive "survival" behaviour. With no, or little, challenge to the existing social conditions it is most often women and children who continue to live in high-risk, impoverished environments with limited access to education and support services.

Currently, there is very little information on the personal experiences of mothers whose children are diagnosed with F.A.S. But women who are at a high-risk for having a child, or children, born affected by F.A.S. experience and live in a society which is largely based on gender-biased social conditions, impacting their own and their children's lives in profound ways.

Crabtree Corner in Vancouver provides daycare and other services to women in the downtown Eastside. In Betty MacPhee's (1992) article entitled "Fetal alcohol syndrome: education and prevention", she has identified some of the environmental issues affecting the women who use Crabtree's services:

- poverty,
- women who are shelterless, who live in hotel rooms, rooming houses or shared space,
- women who are economically and socially disadvantaged, physically, mentally and educationally handicapped,
- women who may suffer from FAE,
- women who have suffered multiple traumas, including multiple family deaths, physical, sexual and emotional abuse, as well as racism and sexism,
- poor health,
- lifestyle factors including multiple partners, drug/alcohol use which causes high-risk behaviour and may lead to a variety of other health problems which include STDs and H.I.V.,
- single mothers,
- high rent costs and poor refrigeration means poor nutrition, lack of adequate clothing, poor health.

These factors contribute to a possible high-risk environment for F.A.S. births. When women live in Vancouver in these conditions and have a child born with F.A.S., Hinchliffe, Abrahams & Wittman (1991) write that they very often have:

...fears of the "system." Stories of babies being apprehended at birth are common in this inner city, as are tales from the United States, where women in this situation are being prosecuted for abuse and providing drugs to minors" (p. 1934).

Clearly, no woman is free from the daily effects of the environment in which she lives and child apprehension and legal sanctions are a few of the most severe societal reactions to F.A.S. that women may face.

There also exists literature that discusses the fact that women who do have alcohol and/or drug problems experience stigma, which may lead to further practice of their addiction and feelings of guilt, shame and a lack of hope.

Finkelstein, et al., developed a program to reduce maternal guilt by helping women recognize that they and their families were victims of alcoholism and that inappropriate

behavior while drinking was neither deliberately malicious nor voluntary (cited in Weiner & Morse, 1991; p. 4).

Generally, however, treatment programs are not necessarily sensitive to women's needs, particularly in detox centres. And, in Canada, there is a lack of pre-natal and post-natal programs for women seeking addictions treatment (AADAC, 1993). Few counselling and therapeutic programs exist which help women to overcome their fears, grief, guilt, while leading them to other supportive environments, programs, education, proper housing, medical care, and overall services that are gender and culture sensitive.

There are some studies being conducted on the influence men have on their female partner, her drinking habits and fetal exposure to paternal alcohol consumption. In animal studies it is believed that paternal alcohol exposure does cause birth defects in offspring (Abel, 1992; Abel & Lee, 1988). These birth defects seem to effect behaviour of offspring, while producing a limited effect on physical characteristics. It is not really known what kind of impact paternal alcohol consumption has on the human fetus. However, studies have shown that when a father supports his partner to stop or reduce her alcohol intake, this behaviour can positively effect a woman's behaviour by encouraging her to lower her alcohol consumption (Canada, 1992, September/October; Ottney, 1991).

With all these factors in mind, any woman of child-bearing age could have a child affected by F.A.S.

With the extra responsibility of pregnancy and the lack of services, women who have been low risk can become high risk to themselves and their children very quickly. This is true for all social-economic and cultural groups of women (YWCA, 1993; p. 5).

Society condemns women for having children who are born with F.A.S., through public and private ostracism and stigma. But, if the environment itself helps to create and perpetuate this disease by allowing such things as high rates of child poverty, on a greater scale we must

measure what responsibility society feels it has to its individual members. Societal pressure and gender stigmatisation victimises women through the creation of social conditioning and misogynist environments. We then blame and shame women for behaviour that is often used as a way to cope with gender-biased living conditions perpetuated by us all. The literature suggests that the simplest, most productive and cost-effective solution to F.A.S. would be to become more responsive to issues surrounding the prevention of the disease (AADAC, 1993; Harwood & Napolitano, 1985). In effect, if women had more access to such things as F.A.S. resources and support services, punishing women for our greater societal problems would not be at issue. And yet, ironically, all the social and gender issues surrounding F.A.S. contribute to its lack of priority as a crisis in our society.

#### Economic Implications

It is impossible to assess the real price paid by each child who is born with F.A.S. and the toll it takes on their families and communities. It is, however, possible to establish how much in financial terms a child with F.A.S. will cost in special services during her/his lifetime. The more intense the child's difficulties are the more costly is intervention and medical care (Harwood & Napolitano, 1985). This disease is extremely expensive to treat because of the multiplicity of problems that must be treated all at the same time.

Henrick Harwood and Diane Napolitano wrote a paper in 1985 entitled, "Economic Implications of the Fetal Alcohol Syndrome". They calculated both the expense that this disease incurs per person (based on services used by individuals at various ages) and the national costs for the U.S.A. (which depend on estimated incidence rates of F.A.S.), including productivity losses for each individual over a lifetime. The researchers also note the policy implications of the overall economic costs of F.A.S. Special services that are used by people affected by F.A.S.

(according to age) include: neonatal intensive care, hospital evaluations, annual check-ups, corrective surgeries, remedial and special education, rehabilitation training programs, as well as living accommodation requirements (residential facilities, group homes, etc.), personal care and institutionalisation for those people most severely affected by F.A.S.

The authors, Harwood and Napolitano (1985) analysed overall costs of the syndrome depending on various proposed incidence rates of F.A.S. in the U.S.A. For the year 1980, at a 1 in 1000 F.A.S. incidence rate, health treatment costs for neonates accounts for \$14.8 million, for children 0 to 18 those treatment costs are \$670 million in 1980, and for adults treatment costs rise to \$760 million (Harwood & Napolitano, 1985; p. 41). These costs include health services, education and non-medical services. In the worst case scenario in this research, with F.A.S. occurring once in every 200 people, costs rise dramatically and services for adults alone rises to \$1.7 billion in health costs and \$2 billion in non-medical costs (Harwood & Napolitano, 1985; p. 41). These figures point to a huge economic investment in treating those affected by F.A.S.

There are no current comprehensive cost studies in Canada on the treatment of F.A.S. Looch (1990) notes that these costs are very difficult to calculate in Canada because of the variety of services needed by each individual affected by F.A.S. It is proposed that the estimated cost per child could be in the area of over \$1 million during a person's lifetime (MacPhee, 1992; May & Hymbaugh, 1983). Many researchers, including Harwood and Napolitano (1985), suggest strenuously that the cost of F.A.S. prevention programs is far less expensive for society, both in financial and human terms. May and Hymbaugh (1989) point out, "The National Indian FAS Prevention Program ultimately cost slightly over \$300,000" (p. 517). Therefore if one child is prevented from having FAS because of a prevention program, in economic terms the program

has already paid for itself. The next piece of the puzzle necessary to fully understand this disease will come through further research.

### Current Research

The current research in Canada on Fetal Alcohol Syndrome is very limited. Asante (1981) writes that "There has been very little mention of FAS in the Canadian medical literature" (p. 331). Studies have taken place in only a few places in Canada (Loock, 1992), and as has been previously stated in this paper, an over-representation of First Nations communities has been focused on in Canadian F.A.S. research (Canada, 1992, December). To my knowledge, the most current F.A.S. research that has been conducted in British Columbia is taking place at the University of Victoria. Normand and Rutman in conjunction with the Ministry of Social Services are currently producing a paper on "Caring for Children with Fetal Alcohol Syndrome" (1996).

Part of the reason for the lack of research on F.A.S. is that it is only since 1973 that Fetal Alcohol Syndrome has been studied as a unique disease. Prior to the labelling of F.A.S., research in alcohol related birth defects (ARBD) did not connect the specific set of criteria needed to establish a diagnosis of F.A.S. Therefore, the specific pattern of problems forming this Syndrome was not approached in a holistic fashion, but an individual's difficulty or disability (eg. learning disabilities, or growth deficiencies) was researched and treated as a separate area of investigation, prevention and treatment planning (Graham-Clay, 1983).

Carney and Chermak (1991) suggest that current F.A.S. research needs "greater control of environmental, cultural, and cognitive variables" (p. 132) because of bias in the study of this disease such as focus on the First Nations population. The literature describes how many researchers, doctors, social workers, caregivers and others are promoting the need for further

F.A.S. research in many areas, including longitudinal studies, management strategies, prevention programs, treatment and epidemiological issues (incidence and prevalence of F.A.S.), educational interventions, and legislative interventions (Canada, 1992; Looock, 1992).

Current research literature that is available on F.A.S. includes a large representation of medical and clinical descriptions of the physical symptoms and conditions caused by the Syndrome. These studies range from reports on the effects of alcohol on animal fetal growth (Abel, 1981; Abel, 1980), to autopsied brains of infants which are examined for ethanol levels (Clarren, et al., 1978). There is some literature, formal research and community-based information that has been written on prevention programs for specific communities. Finally, few writings exist on treatment strategies for those families whose children are affected by F.A.S. This literature usually focuses on therapy for the alcoholic mother, as opposed to solutions, management strategies and therapy/counselling for families dealing with a child born affected by Fetal Alcohol Syndrome (Funkhouser & Denniston, 1985; Looock, 1990). As research directly informs public policy, its impact on the public is profound.

### Policy Issues

There are many issues involved in designing public policy regarding F.A.S. Planning for this disease is controversial and emotional because F.A.S. is one of the leading causes of mental retardation and yet it is preventable. Opinions about this disease can vary widely, but public disapproval, denial and anger about the way in which F.A.S. is caused does sway government and public monies away from this research area despite the fact that F.A.S. continues to grow in prevalence across the U.S.A. and Canada (Asante, 1981; Harwood & Napolitano, 1985). Unfortunately, public shunning of this issue is only delaying the prevention strategies that need to be put into place in order to curb this growing disease.



This thesis will not provide an in-depth review of policy regarding F.A.S., but I would like to suggest two books that do look at public policy regarding this syndrome. Laura Corkery Best's 1993 book, Guiding Our Children Beyond Risk: A Handbook for Caretakers of Prenatally Drug Exposed Children (2nd ed.) explores a variety of policy issues. She includes information on universal testing for F.A.S., mandatory treatment of mothers who are at-risk of having an F.A.S. baby with the threat of incarceration, mandatory child abuse reporting, and segregation and/or labelling of F.A.S. children. These issues are demanding of well-thought out public policy and need to be thoroughly examined and debated by committees of individuals familiar with F.A.S.

Another book that delves into F.A.S. public policy is What You Can Do to Prevent FETAL ALCOHOL SYNDROME: A Professional's Guide by Sheila Blume (1992). Blume discusses policy regarding the prevention of F.A.S. She focuses on educating those people who deal with F.A.S., including professionals, the criminalization of alcohol and other drug use during pregnancy, and a variety of other policy issues. Again, the public debate of these issues is timely and discussion of these areas with informed experts, especially families affected by the disease, will be extremely important to the formation of effective prevention and treatment programs.

### F.A.S. Prevention

Fetal Alcohol Syndrome is plausibly completely preventable. If a woman abstains from drinking alcohol while she is pregnant there is very little question about whether her child will be born affected by this drug. It should be noted that besides maternal alcohol consumption there are a variety of other environmental and physical factors that will affect the health of a fetus. But, with proper preventative measures, it is possible to ensure that F.A.S. and its terrible consequences no longer remain the leading cause of mental retardation in children.

In the literature, prevention of Fetal Alcohol Syndrome seems to focus on three general areas of concern. One area of attention highlights education of the general public and professionals about F.A.S., the second area concentrates on the mother who may be drinking while she is pregnant, and the third area is focused on providing intervention services for those families affected by F.A.S. These prevention concerns are attended to differently depending on a variety of factors. For instance, in "FAS/FAE: Focusing Prevention on Women at Risk", Weiner, Morse and Garrido (1989) suggest that the three branches of prevention planning include "primary" strategies which focus on education campaigns and their effectiveness, while "secondary" and "tertiary" prevention includes a focus on treatment of addictions, particularly during pregnancy.

Other factors affecting prevention program design are the needs of a particular population, the services readily available to them, the researcher (his/her own biases), specific program goals, monies available to the program, and support of the program in the community and by other agencies (AADAC, 1993; Funkhouser & Denniston, 1985). As well, literature suggests that it is important that prevention planning include gathering a diverse group of agencies together in order to design an effective prevention program for a specific community

(MacDonald, Bibber, Najak, & Peekeekoot, 1991) for there are multiple problems caused by F.A.S. It seems that if many different agencies may have the opportunity to promote F.A.S. prevention to families, a variety of agencies at community, health, social service, voluntary and other levels must participate in collaboratively constructing an appropriate prevention strategy for their own community.

The professional community, caregivers and activists note that many activities and projects may be involved in forming prevention strategies such as planning F.A.S. public information and awareness campaigns, as well as local educational programs (MacPhee, 1992). Professionals can identify risk groups and offer these families special services making sure families are being referred to effective service programs (AADAC, 1993). As professionals, we must also ensure all health care, social services professionals and the public are sensitised to the needs of mothers who are addicted and/or who have children with F.A.S. (Rinkel, 1992). Finally, communities need to develop local resource centres regarding the disease and encourage the community to be involved in the health and program planning of its own population (AADAC, 1993; MacPhee, 1992; Prugh, 1985).

### Programs

In Thomas Prugh's 1985 paper entitled, "F.A.S. Among Native Americans; Detection and Prevention", there is a discussion regarding a prevention program in a particular First Nations community. Prugh's pilot prevention project was focused on educating clinicians and prevention specialists about F.A.S. The clinicians were trained to recognise and treat Fetal Alcohol Syndrome and also served as regional consultants on the Syndrome, while the prevention specialists learned to disseminate information on F.A.S. The prevention program

included development of a Fetal Alcohol Syndrome resource centre. The program also provided outreach services for women and their F.A.S. affected children.

Masis and May (1991) describe the planning model used for a prevention program in Tuba City, Arizona for the Navajo Area of the Indian Health Service. F.A.S. prevention was viewed from a systems perspective, using individual, family and community based strategies to encourage prevention. Primary prevention (awareness), secondary prevention (screening women for alcohol use and providing them with information on the subject), and tertiary prevention (counselling, support and services for those pregnant women who were heavy drinkers, who were at-risk during pregnancy or were mothers of previous F.A.S./F.A.E. children) were used conjunctively.

In the Masis and May (1991) project, a clinic was held 5 times between January 1988 and July 1989, to examine and diagnose children with F.A.S. Public education was a large focus of the project through schools, at community presentations, meetings and in the local media. The program was multi-faceted to fit the needs of the clients and raise awareness in the community about F.A.S., staff members included Navajo residents and a family-oriented approach was used in the program. This program had an extremely high participation rate. Forty-eight women were referred with only three refusing to participate, which resulted in a general and overall heightened awareness in the community about alcohol abuse.

Three large Canadian projects have also been developed to provide information and services specifically aimed at women who are pregnant. The Healthy Babies program offers mostly educational activities concerning maternal health and high-risk behaviour during pregnancy to the public (Canada, 1992, December). The Brighter Futures Community Action Program has also been designed to improve the health awareness of women who are targeted as

having high-risk pregnancies (Canada, 1992, December). A focus in this program is on drug and alcohol consumption during pregnancy in the preconception, prenatal and postpartum periods.

Finally, Asante and Robinson (1990) discuss the Pregnancy Outreach Program (POP) which was designed in 1988 to help improve the overall reproductive health of women with high-risk pregnancies. The POP program tried to effect changes for women:

- 1) to reduce at-risk behaviour associated with poor pregnancy outcomes and 2) to educate physicians and other health workers about the alcohol and drug effects on pregnancy. The five health behaviour changes to be measured are improved nutrition, decreased smoking, decreased alcohol and drug use, consistent emotional support, and increased breastfeeding (Asante & Robinson, 1990; p. 76).

It has been noted though, that the POP program needs to work in conjunction with other community programs to be more effective (Robinson, Armstrong, Moczuk & Loock, 1992).

An excellent source of information on how to initiate and plan a prevention program is available in the FAS/FAE and NAS Community Prevention Guide (1993), written by staff members at Vancouver's Crabtree Corner in conjunction with the B.C. Ministry of Health. This guide provides the reader with a series of topics that help to develop awareness about FAS and other drug effects on mothers and children. It also discusses factors involved in developing a successful F.A.S. (F.A.E. or N.A.S.) prevention plan. This guide provides an excellent framework from which any other community might be able to form their own prevention program and/or strategies. The guide does not limit itself to a rigid plan of action, but provides a variety of helpful suggestions and strategies which encourage awareness, discussion and community program planning. The next section reviews treatment for families affected by the disease.

### F.A.S. Intervention

Finding effective intervention strategies for families who have a member affected by Fetal Alcohol Syndrome is a complex matter. Intervention can be expensive, as well as difficult to plan and manage (AADAC, 1993; Harwood & Napolitano, 1985). Treatment is dependent on availability of accessible resources, the openness with which a family approaches treatment and the knowledge a clinician or social worker/counsellor has about F.A.S. (AADAC, 1985; Rinkel, 1985). It should be noted that it is very often parents who become case managers as they skip from organisation to organisation trying to design, plan and manage their child's treatment needs. As the Syndrome becomes more well known to agencies and professionals, and organisations (hospitals, clinics, schools, and other agencies) work together to plan for a child affected by F.A.S., case manageability will become easier (MacPhee, 1992).

The best case scenario for intervention would be to provide services to a family early enough to avoid further complications of the syndrome. For example, Weiner & Larsson (1987) write that "when a woman stops drinking heavily there is a chance for an improved fetal outcome" (p. 60). Thus, helping the mother to stop drinking while she is pregnant would increase the chances for her child to be less affected by F.A.E. or F.A.S. Currently, some clinicians may use a series of questions developed specifically to help identify women who may be seen as high-risk for drinking while pregnant. The T-ACE questions are as follows:

T(Tolerance): How many drinks does it take for you to feel high?

A(Annoy): Have people ever annoyed you by criticizing your drinking?

C(Cut down): Have you ever felt you ought to cut down on your drinking?

E(Eye-opener): Have you ever had a drink first thing in the morning to steady your nerves? (Lena Productions Inc., 1992; p. 2)

Unfortunately, even if a service provider identifies through assessment a high-risk pregnant woman, providing them with treatment is another extremely difficult task.

Women may deny or minimise their drinking behaviour or habit, they may not have access to information about the effects of alcohol on their fetus, and they may live in an environment and/or with a partner/family that does not allow them to address their alcoholism or drug addiction (Loock, 1990; MacPhee 1992). As Loock (1990) writes:

A woman may be reluctant to enter a treatment program (e.g. fear of family disruption and apprehension of children) or she may have difficulty dealing with traditionally male oriented treatment strategies. The relatively short duration of pregnancy precludes programs with long waiting lists. ( p. 4).

Her situation may be made even more complicated if she is dealing with her own suspected F.A.S. or F.A.E. that has not been diagnosed and she is trying to cope with pregnancy without the benefit of successful management strategies for her own life (Canada, 1992, September/October). Finally, many women who are identified as being high-risk already have children, who may or may not be F.A.S. affected, which makes conventional residential treatment programs very difficult to undertake (Canada, 1992, September/October; Rinkel, 1992).

Women who want to stop drinking, or who need intervention after their child is born and diagnosed with F.A.S., have very specific needs. As Betty MacPhee (1992) has identified:

A model to assist women struggling with alcohol dependencies should include prenatal care, alcohol and drug services, women-specific detoxification and treatment centres which include children. There exists a need for affordable, safe and secure housing, respite care for the mother, infant development personnel, child care for the children, special needs day care spaces that are adequately funded, health personnel who are in the community and on-going support groups for parents (p. 377).

These services require a great deal of planning, organisation, funding and inter-agency co-ordination. There is currently no one agency in British Columbia that can provide the multiplicity of services needed for a woman who is identified as at-risk, or for women who have children who are diagnosed with F.A.S.

Weiner and Morse (1991) note that when a child is born and diagnosed F.A.S., "for optimal development, early intervention with individual instruction and a consistent, supportive environment is required" (p.3). It is suggested that early treatment should include discussion of the diagnosis with the parents, counselling, sobriety issues, medical evaluations and a supportive environment, all with a focus towards helping to develop the potential of the child (MacPhee, 1992). A variety of services should then be identified for the person diagnosed with F.A.S. depending on their age level, whether they are infants, pre-school children, children in middle childhood, adolescents or adults (Olson, Burgess, Streissguth, 1992). As already mentioned, services must be specific as each individual has distinctive disabilities and cognitive needs which are different from other birth defects like Down's Syndrome (Streissguth, 1991). The overall treatment approach including increasing a client and family's F.A.S. knowledge, organising services, paying medical and other expenses, learning parenting skills and providing a healthy living environment for a child, with lots of community support needed to help clients reach their developmental potential is an overwhelming task for counselling and medical services as they are currently structured.

### Caregivers

There are special issues that must be attended to for caregivers of F.A.S. affected children. Parents must deal with their own addictions, guilt, anxiety, grief and societal pressure regarding their F.A.S. affected children, while adoptive and foster parents will deal with other issues regarding their child's birth family. Both birth parents and other caregivers need to learn about their child's diagnosis and what it means, then get support and guidance for their child's behaviour, find school programs to help their children, understand the needs and issues of developing children, find respite care, support groups and counselling, and plan for any financial



and custody issues regarding their biological or adopted children (AADAC, 1993). As well, all caregivers need inexhaustible patience as they deal with the web of health and social service agencies providing help to their child and family.

Parents and other caregivers must then learn to organise their child's life and future, co-ordinating the many professionals involved in the planning. They will need to learn how to deal with their own child's questions, behaviour and disabilities with appropriate management techniques. Management may include targeting a child's functional skills and focusing on the development of these skills, as well as teaching children communication and social skills (AADAC, 1993). Anne George, with the assistance of Norma Carey, has written a Guide for Parents, Teachers and Others Caring for Children with FAS/FAE and NAS (1993) for YWCA's Crabtree Corner. This guide helps provide specific tools and resources that caregivers can use to help children manage their behaviour. This guide is written in a way that accentuates a child's positive attributes and skills.

### Professionals

There are a number of issues that also need to be addressed by professionals providing services to families affected by Fetal Alcohol Syndrome. Perhaps the most serious issue is that professionals themselves need to become more aware of this disease and how it can be treated and managed. It has been noted by the Canadian Centre on Substance Abuse (1992) that in a survey of Canadian medical schools almost no training is done on alcohol and drug problems. There is a definite need for curriculum to cover information on this subject and for more research in this area. Weiner, McCarty and Potter (1988) hypothesise that lack of clinical intervention for alcohol problems during pregnancy are caused by the:

...professionals' lack of knowledge in three areas: the mechanisms of alcohol's actions and effects during pregnancy; specific treatment techniques; and referral resources (p. 21).

Solutions must be designed to encourage professionals to develop their knowledge about this disease and its effective treatment.

Training programs, such as "A Successful In-Service Training Program For Health Care Professionals" (Weiner, Mccarty & Potter, 1988) can be held for and attended by professionals dealing with Fetal Alcohol Syndrome. This program encourages improvement in professional practice and F.A.S. treatment. It is aimed at helping professionals become more knowledgeable about F.A.S. and its clinical definition, practical strategies for therapy and intervention, and finally, it was designed to allow professionals to assess their own attitudes about women and families facing the issues surrounding maternal alcohol abuse. This training program was rated as above average or excellent by 93 percent of the 748 professionals who had participated. The knowledge resulted in such changes as a greater understanding about alcohol consumption and an increased willingness for participants to discuss F.A.S. with their clients.

The literature is distinctly lacking in information regarding awareness of culture and gender sensitivity when providing treatment and therapy/counselling services to families affected by F.A.S. Clinicians and professionals must be open to working with other agencies/professionals to provide the most comprehensive services for their families, recognising that most individuals with F.A.S. will need some service the whole of their lives (Funkhouser & Denniston, 1985). Jones, Hutchins, and Grason (1990) discuss other issues that produce tension in professional care, such as:

...health care professionals who face confidentiality and liability issues, requirements for child abuse and neglect reporting, and/or lack of adequate referral sources for treatment of the mother and child (p. 15).

And, professionals must be open to allowing community members to help design and co-ordinate services for their own members (May & Hymbaugh, 1989).

The community, professionals and government must work together to provide creative and successful solutions for treating F.A.S. Intervention was a major focus of discussion at the Symposium on Fetal Alcohol Syndrome and Fetal Alcohol Effects held in Vancouver in 1992. Indeed, the bulk of the workshops at this Symposium focused on intervention issues, such as "Mobilizing the health field" and "Making systems more responsive" (Canada, 1992, September/October). Inevitably, as the literature has shown in this chapter, intervention plays a critical part in preventing Fetal Alcohol Syndrome. Without fully understanding the disease, those who are most affected by it, and the economic implications of FAS, effective research, treatment and multi-system solutions cannot be organised. The next chapter deals with the particular cultural and historical context in which F.A.S. is discussed in this research.

## CHAPTER TWO

### F.A.S. IN THE CANADIAN FIRST NATIONS COMMUNITY

Native Nations have always fought and continue to rebel against their oppression. Unfortunately, some of the ways in which we have resisted, through violence, alcohol and drugs, have only furthered the efforts of colonialist forces of assimilation begun at contact. This thesis does not extensively explore the problem of violence or addictions in the First Nations community, but strives only to show the strong connection of First Nations intergenerational responses to legalised and legitimated injustice and oppression. Indeed, the term "coping skills" in regards to Aboriginal people may need to be redefined in order to honour those First Nations people who have used alcohol and drugs to medicate themselves from the pain of colonisation that continues to be practised today.

Among the many ways that First Nations people in Canada have fought oppression, alcohol has been used to control and numb our collective grief. As Johnson (1987) says in Going out of our minds: The metaphysics of liberation, "we keep adapting to new and ever more dangerous conditions and ideas. What should seem horrendous comes to seem normal" (p. 235). Herbert (1994) mentions in her M.S.W. thesis there has been no clear way of documenting the extent of the alcohol problem in the Native community for a variety of reasons, although there is a consensus that this problem does exist in the community.

Alcoholism as it is practised in the First Nations community is a topic for research in and of itself. Alcohol as a coping tool can be connected to the devastating current repercussions of Fetal Alcohol Syndrome in the First Nations community. It is the sheer strength of Native people and culture that has guided them through their experience of colonisation, but they have not escaped unharmed. The tools of survival and resistance have been limited, and I believe, one

of those tools, alcohol, continues to promote further disintegration of the First Nations community.

In acknowledging the problem of alcoholism and FAS, and the extent of the problem in the First Nations community, I am most concerned about how to examine this issue in a holistic way that honours the individuals and community to which I belong. In the examination of history connected to voice, I find myself trying to explore Fetal Alcohol Syndrome in the First Nations community in a way that will pro-actively engage and encourage thought for change. As Christine Looock (1990) relates, "Fetal Alcohol Syndrome is common, expensive and preventable" (p. 2). In no way do I consider the currently reported high occurrence of FAS to be representative of life in First Nations communities. Thus, despite the severity of the problem and the lack of research which reflects the true nature of the personal, familial, social, and community perspectives and context of the disease, I was encouraged by Elders, colleagues and family to try to present the First Nations practitioners' stories regarding this syndrome in a respectful, honouring and thoughtful voice.

This research investigates how we as First Nations practitioners use our tools, skills and abilities with our people. It is an examination of our own views towards counselling families affected by F.A.S., and it allows us as professionals and lay-people to hear the powerful and wise voice of the First Nations counsellor. I believe the opportunity to use this devastating disorder as a tool to uncover the ways in which we as counsellors work with our own people is, in fact, a way in which I can humbly contribute to the strength of the Aboriginal Nations.

Oppression and rebellion are distinctly connected. Oppression forces a people to make serious choices and it has caused Aboriginal people to rebel and survive with the skill and dignity that comes from inner strength. The illusory path of promise is the one that we follow

without challenging, questioning and speaking. This paper connects the lives and the work of First Nations counsellors to a problem we now face in our community, Fetal Alcohol Syndrome. Systemic discrimination has led to institutionalised repression resulting in First Nations being blamed for their own victimisation. There is no single human solely responsible or at fault for systemic discrimination, indeed responsibility for oppression is not at issue, it is the challenging of racism that is of importance. We are accountable for how we currently behave and treat each other as individuals and therefore, we must also be accountable for how we treat problems which are not simply seated in the body, but in the body politic.

The uncovering of the historical treatment of First Nations is significant to Fetal Alcohol Syndrome because F.A.S. is completely preventable, which makes this disease one that can be attacked through education and not just medication or alcohol treatment programs. In the next section, I wish to add to the collective understanding about illness in connection to history and culture. Aboriginal counsellors and their practices are integral to the healing of F.A.S. in our Native Nations because they are experts on their own history of discrimination, thus making their understanding an essential part of the healing of their own community.

### The Cultural/ Historical Context

Theoretical constructs, working skills and practice grow with societal and personal transformation. Therefore, any discussion about F.A.S. in the First Nations community must include acknowledgement of historical inequity, which has altered First Nations cultures profoundly. Revealing the context of this disease as it exists in the First Nations population will help uncover the truths about our lives and will lead to wisdom in preventing and treating F.A.S. The issues surrounding this disease such as diagnosis, economic implications, current research,

prevention and intervention impact the First Nations community in very specific ways which has resulted in our particular disempowered historical position within Canadian culture.

History plays an integral part in my choosing to explore the topic of First Nations counsellors' experiences with First Nations families affected by Fetal Alcohol Syndrome. The degradation of First Nations culture and tradition after European colonisation has resulted in incredible community turmoil. This degradation of culture has also had a profound and long-lasting effect upon the Canadian government's political agenda regarding the health of First Nations people which was disregarded in lieu of assimilation and integration policies (Frideres, 1988). There came a smothering of the beliefs, values and voice of First Nations through the Canadian legal system and discriminatory policy in a variety of arenas including enfranchisement, land treaties and marriage (Frideres, 1988). First Nations could lose or gain their status and rights totally dependent on the values of the non-First Nations population and the variety of legal ways that were used to control and "civilise" First Nations people (Campbell, 1973; Falconer, & Swift, 1983; Haig-Brown, 1991). These policies changed traditional culture, relationships, knowledge and finally, the ways that First Nations approached health, well-being and their own ways of caretaking others in their communities.

Many Aboriginal people live today on and off reserve in poverty and are dependent on government benevolence. Due to Euro-Canadian colonialism a variety of oppressive and racist practices were executed. The aspiration of the European community upon landing in the "new world" was to colonise North America through integration or eradication of First Nations peoples (Frideres, 1988). Contact caused a massive depopulation of First Nations due to disease, often in the form of Tuberculosis epidemics, although many believed, as Jensen and Brooks (1991) note, that "the smallpox was the worst" (p. 26). Warfare, famine, slavery and genocide of Aboriginal

people, such as the Beothuk of the Maritimes, were sanctioned and practised through governmental policy. This encouraged tribal disintegration, hostility and economic dependence on European colonialists (Frideres, 1988).

As time progressed, a variety of other tactics were used to "assimilate" First Nations people into Euro-Canadian society when it was found that the First Nation population could not be "eliminated". Residential schools were particularly effective bastions of Aboriginal control and cultural invasion (Haig-Brown, 1991). Christianity was also used as a tool to "civilise" First Nations people into conforming to Euro-Canadian expectations and cultural standards (Campbell 1973; Falconer, & Swift, 1983). First Nations were moved to reserves, literally, camps wherein Aboriginal people to this day are controlled by government and ostracised by the rest of society, as Geoffrey York discusses in his book The Dispossessed (1992). These interactions between Euro-Canadian and Aboriginal peoples have formed a framework of institutional oppression and systemic discrimination which continues to devastate First Nations to this day.

Frideres (1988) notes that colonisation through assimilation and eradication of Aboriginal peoples comes from a particular theoretical orientation which guides beliefs about the ways in which people do and should interact in the world. The beliefs and values of Euro-Canadian culture and that of First Nations people were, and are, vastly different in their relationship to the physical environment and human interactions. Indeed, before European contact as Kwagwiltz Elder, Daisy Sewid-Smith (1991) relates:

The tribes and clans of the Indian nations of British Columbia were fully developed during this period. They had a large population and they had developed a social system so impressive that apparently a group of Buddhist priests visiting what is now British Columbia in 458 A.D. called it a "land well organised" (p. 19).



Pre-contact complex and thriving communities of people existed. Aboriginal peoples' conceptions of human nature and social organisation were holistically-oriented having evolved over thousands of years of practice (Connors, 1993).

Mercantile capitalism played an important role in the destruction and disruption of the lives of First Nations (Frideres, 1988). Mercantile capitalism focused on trade and exchange, based on capitalist ideology. One of the main motives to come to the "new world" was the economic opportunity that existed in the land and its resources. This economic system arose in Europe in the 14th century, when the Hanseatic Trading League promoted the use of trade and resources as a colonising agent in Africa (Frideres, 1988). In the new world, there were furs, tobacco, and other resources that could be exploited by the colonising agents of Britain and France.

"Manifest Destiny", the belief that whites should control the world or most of it, and the idea of "incorporation" which Thomas Hall coined to encompass the idea of bringing Aboriginal people into the European world and creating markets in this new land where no mass markets existed before, were the leading ideologies at the time of contact (Frideres, 1988). The idea that white Europeans were superior to Aboriginal peoples because of their complicated market system, technology, implements, and political and/or moral perceptions, created a racist society within which Native Nations continue to struggle for survival (Frideres, 1988).

James S. Frideres (1988) in Native peoples in Canada suggests that the treatment of Native Canadians is based on racist ideology. Racism is a way of categorising the systematic mistreatment experienced by First Nations and other people of colour. This mistreatment generates misinformation about a people, disempowers them, solidifies internalised oppression in

people of colour, and serves as a strategy to divide and conquer a people which then becomes further justification for mistreatment.

Racism has been incorporated into a variety of ways that Europeans have historically dealt with First Nations people. Fundamentally, Aboriginal peoples were and are considered wards of the government. This moral, legal and political definition is responsible for First Nations being treated like children to be seen (not too often) and not heard. Racist foundations can be viewed throughout Canadian governmental policies that specifically oppress First Nations. For example, the connection of Aboriginal peoples to their land is most important to First Nations survival and identity, and historically, First Nations treaties and land claim cases have not been made a priority by any Canadian government despite political rhetoric. Putting First Nations in conflict with the government over such important and fundamental issues, as well as limiting access to resources and economic self-sufficiency, has allowed First Nations little recourse to change their disempowered situation.

The European understanding of Aboriginal people comes through quite clearly in the way that perceptions of Aboriginal spirituality, living conditions, and education systems are discussed in historical texts. Very telling is the fact that contributions by First Nations are almost never included in formal historical documentation. History, law, political, medical, moral and other written words came to be documented without First Nations representation in Canada. As Celia Haig-Brown (1991) notes in Resistance and Renewal, oppression has become a matter of governmental policy and all records of historical fact are written by the oppressor. This has been an avenue through which Euro-Canadian society has maintained control of Native Nations, land and resources. Allowing only one legitimate recording of history has restricted and often cauterised the Aboriginal voice.

Labelling, trivialising, and stereotyping First Nations has also allowed the dominant society certain privileges. The status quo is set up to protect the rights of already privileged peoples in this society, and thus lends less legitimacy to those people who are negatively portrayed or completely forgotten about in history books and, thus, in people's minds. As Frideres (1988) has stated, "whether blatantly or covertly, most Canadians still believe that Natives are biologically and socially inferior" (pg. 5). Aboriginal peoples are "victims of cultural invasion or dislocation" and most all institutions set up to deal with the First Nations population were used to ensure Native dependency and oppression in Canada (York, 1989). Institutions built on racist ideology have helped perpetuate and justify beliefs in white society that Aboriginal people were savages, heathens, had no education, and lived in filthy conditions until the white man came to "civilise" the people.

Systemic discrimination and racism have led to such things as sickness, poverty, inequality, addiction and internalised oppression which have all contributed to post-contact Aboriginal identity problems (Brown, 1986). Internalised oppression is expressed in Canadian Aboriginal identity through various behaviours and realities that exist in First Nations communities. For instance, because of such things as low self-esteem, loss of pride in culture and little knowledge about traditional practices, many modern First Nations people have had little, or no, education in their own language and cultural practices, high rates of child apprehension (and placement in non-Native communities) exists, high Aboriginal representation in jails occurs, and alcohol, as well as drugs (York, 1992) are used to fight racism and isolation. Finally, a high suicide rate in the Aboriginal population (Cooper, Karlberg & Adams, 1991) is a manifestation of the sad internalised belief that life as an Aboriginal person in this society is not worth living, or it is too painful to continue.

Perhaps the most telling example of systemic discrimination and racism exists in the residential school experience, which was believed to be the way in which Euro-Canadians might assimilate First Nations into "white" society. As Celia Haig-Brown (1991) reveals in Resistance and Renewal, First Nations culture "was seen as something archaic and undesirable, something to be annihilated" (P.58). Academic skills and studies replaced traditional learning techniques, and the old ways of hunting, fishing and gathering foods were discouraged. The loss of home life, family, dances, celebrations and spiritual practices brought loneliness, often alcoholism and the inability for generations of residential school participants to parent their own children. Even more devastating, these schools did not teach the children practical skills to enable them to work at jobs in the Euro-Canadian world once they left this isolated existence (Haig-Brown, 1991). This school system further affirmed hopelessness (isolation and degradation), poverty (the welfare system) and alcohol/drug abuse as well as dependency on the Euro-Canadian community (for all essentials), leading to further broken Native hearts and spirits (Haig-Brown, 1991).

Unfortunately, all these "problems" seen in the First Nations community are then used by white society to further support and perpetuate racist ideologies. Many North Americans still believe in the media images of lazy, stupid, and drunken Indians. When First Nations take control of their lives they are criticised harshly by society for being "radical" and dangerous, such as those Natives that speak out about land claims and other societal injustice. A strong example of this cycle is apparent in the political and moral judgement and criticism that was meted out by the press and general public upon those individuals who took action at Oka, Quebec in 1990.

Racism and systemic discrimination have become enmeshed with the patriarchal and Euro-Canadian theoretical perspective that allows power relations in politics to favour particular

groups of people to the detriment of others. However, it is important to note that racist policies of the past are not as politically acceptable as they once were. Today, First Nations are demanding more from their governments, as well as taking action to retrieve and stabilise their natural rights. For instance, many First Nations express their varying opinions regarding many subjects in forums that include Aboriginal newspapers like British Columbia's "Kahtou", conferences on Aboriginal rights, and rallies held to protest government actions.

At the same time though, popular in the media and the First Nations community is the promotion of the idea that the oppression of First Nations people can and will be turned around through the practice of self-government. It has been put forward by politicians and others that a process of de-colonisation can be inspired through First Nations governments, as opposed to the modern way that Native Nations are regulated by the Canadian Federal government (Frideres, 1988). Effective self-government is touted as a means of challenging the system through direct First Nations control of politics, economics, health and social welfare. But, as Carol Lee Sanchez (1988) has said about such tactics, "...stop colonizing us and reinterpreting our experience" (p. 166). Clearly, when recognising the reality of First Nations history, it is important for Aboriginal people to ask themselves if it is truly possible for self-determination to exist within a Euro-Canadian biased interpretation of institutionalised government.

Both the federal and provincial governments officially recognize the concept of First Nations self-government to be legitimate. But, First Nations people are wary of the agreements that look so much like the paper that many treaties were written on. Historically there has not been much change in the government's approach to self-determination and Aboriginal people are cautious when they hear promises. For instance, regarding the federal government, Ovide

Mercredi, the Chief of the Assembly of First Nations, made this remark on his return from travelling throughout Canada:

" 'Some of our people are very cynical and don't even give the Liberals a chance' " ((Appelbe, 1993; p. 3).

But, First Nations people are more than cynical, they are exhausted from fighting colonialism, racism and institutionalised oppression.

First Nations resistance to colonisation and racist practices has encouraged a societal reaction towards Aboriginal people primarily limited to sympathy, anger, and broken promises. First Nations action against oppression has not been effective in incurring positive, long-lasting change in living conditions for Native Nations because of the absolute governmental control of such things as money, material resources (adequate food and shelter), formal education and social services. As Stephen Hume (1995) writes so eloquently in "The Vancouver Sun" regarding land claim settlements:

Descendants of those white settlers enacted other racial exclusion laws to consolidate their holdings while beggaring the original occupants. And now we must listen to the argument that First Nations' attempts to regain equal access to the economy through an adjustment to the imbalance in land tenure born of racial discrimination amounts to racial discrimination? This is the hypocrisy of naked greed at its most odious (p. A15).

Blaming the victim has come to be a common experience for Aboriginal peoples in Canada.

And, the words of First Nations that reveal the inequities of the past are often dismissed, denigrated or removed from view.

The mental, emotional, spiritual and physical well-being of First Nations in Canada has been keenly influenced by social work practice. Indeed, what has not been my direct personal experience as a mixed-heritage Native woman, I have often seen revealed in my life as a multigenerational issue passed on to me as part of the legacy of my culture. The recognition of the genocide, systemic discrimination and racism perpetrated upon First Nations has become a

great part of the impetus for my choice to practise social work and counselling. It is with my limited and sole experience, that I acknowledge the historical injustice existent in my own chosen professional field and how it has been and is practised in First Nations communities.

The state of Aboriginal health and social services delivery can only be fully comprehended within the above outline that explores the context of historical efforts to destroy First Nations people (Connors, 1993; McKenzie, 1985). Both the Canadian public and the powerful federal political systems consistently limit First Nations control over the health and well-being of their own populations. As Carol Lee Sanchez (1988) describes:

...the spiritual and psychological violation of Indian people trying to live in the dominant [domineering] culture generally forces us to numb ourselves as frequently as possible (p.165).

The real psychic and physical pain initiating from racism and oppression has become epidemic in the Aboriginal community. And, the ways in which counselling and the practice of social work are offered to First Nations does not reflect understanding of colonialism and the intergenerational repression affected by this process.

For instance, the traditional provision of social service delivery to First Nations communities has been through ethnocentric treatment models and counselling programs (Falconer, & Swift, 1983). Social work has historically responded to and been formed from a tradition that is based on charitable European organisations (Guest, 1991). Problem definition and response/intervention often occurs on the level of personal interaction alone, ignoring needed change to social conditions and therefore proving to be ineffective, even damaging, to First Nations communities. Perhaps the most explicit example of this orientation to service delivery is apparent in the massive apprehension of individual Aboriginal children practised in child

welfare, that has been an acceptable dominant culture answer to intergenerational issues of familial poverty and despair.

The Euro-Canadian value orientation behind social service intervention has been cruelly exacted on First Nations communities. As Falconer and Swift (1983) note:

For many years, the general belief among Canadians has been that Natives would gradually disappear as a distinct group. They would become assimilated by the dominant culture. Many of our policies, including child welfare, have been based on this belief (p. 187).

This belief, realised in governmental agendas has served to reinforce the breakdown of the First Nations community, seen particularly in the use of drugs and alcohol. First Nations have used addiction in an effort to dull the psychic pain existent within the community due to such things as the "sweep of the '60's" when Native children were taken from their parents, culture and communities en masse and put into foster homes or adopted to other communities, even countries.

This history of oppression has led to social work practice which has remained consistent with dominant cultural values. Therefore, traditional social work itself has become a part of the very problem that First Nations need to avoid in order to effect positive changes in their communities. Social work must deal with health issues, for the well-being of an individual is largely what determines a client's strength to challenge and change her or his situation at a personal and social/political level. Therefore, the design of addiction treatment programs for Aboriginal people, including offering services to those affected by F.A.S., must include a socio-political and cultural/historical theoretical framework. In the process of taking control and improving life conditions the solutions to institutionalised policy must be found outside the colonial structure and ethnocentric service delivery, and inside the hearts and minds of those people who will challenge systemic injustice.



In the final analysis, even the most detailed discussion of racism and oppression cannot possibly uncover or document the literal fear of death because of one's race, colour or people. Fortunately, in light of all this experience there are First Nations individuals such as Mohawk Brian Maracle, who refuses to be silent (York, 1992). He questions the high suicide rates in the First Nations population, "Did these people die because of thousands of individual acts of free will? Or were they driven to their deaths by powerful outside forces that gave them no other choice?" (York, 1992; p. 200). As Native Nations become more powerful self-advocates and activists, as we relearn our cultures, we are beginning to question the powers that be, we are sharing experiences of survival and rebellion, and we are demanding justice for years of injustice.

The documentation of First Nations history and how we have been forced to cope with genocide in modern society is now being recorded. It is often written with the passionate belief that we have survived and now must reincorporate our culture into our lives so that we might regain "wholeness" and thrive as proud people. Unfortunately, F.A.S. is one of the most serious and terrible consequences stemming from the attempted cultural genocide of First Nations. Indeed, internalised oppression has meant particularly devastating repercussions for women in our communities.

### First Nations Women

The rationale and policies behind Canadian government intrusion into First Nations ways of living and relating to all things, have been clear in their orientation to amass wealth and material goods, whatever the cost. But, there have been side effects of this oppression that are not widely recognised or discussed even within First Nations communities. Due to politics, government and Euro-Canadian value systems, Aboriginal women are in a particularly

disadvantaged situation. Pre-contact traditional positions for women in First Nations society have been superseded by the interests of those in power, including both Euro-Canadians and First Nations men.

The Indian Act, written to organise and control the lives of Aboriginal people has been incredibly destructive, reflecting clearly the values of a patriarchal culture. For instance, power relations within the First Nations communities have been reorganised by Euro-Canadian example under the auspices of Band governments led by "chiefs." But, as the membership of the Professional Native Women's Association (1985) have noted, "Band governments" are not traditional First Nations organisations. And, these political organisations do not protect the interests of First Nations women sufficiently, indeed they very often ignore women's interests altogether (Professional Native Women's Association, 1985).

The Indian Act changed the lives of First Nations women in a variety of ways. For example, it denied First Nations women status if they married a non-First Nations man, while men who married non-Aboriginal women were not denied status. Herbert (1994) also notes that:

This blatant act of discrimination based on sex took away the rights of First Nations women to live in their communities, to identify as a First Nations person, and to benefit from the rights available to all other First Nations people (p. 14).

Bill C-31 has been a powerful example of policy attempting to eradicate Native Nations and it is focused primarily at Aboriginal women. As Joseph (1991) discusses, Bill C-31 was written to return rights to First Nations women and their children who lost their status when they married non-Native men. But, only certain First Nations women can regain their status, those who have a specific and documented ancestry. And, the political distinctions between "types" of First Nations people, "non-Status, Status and Metis" have made extreme divisions within the Aboriginal community.

As well, Band membership is at the discretion of Band government which leaves Aboriginal women, who have received their status through the Bill C-31 amendment, at the mercy of Band officials. These leaders decide whether or not mothers and their children may live on reserve and vote in Band elections. Bill C-31 has been a vicious attack on First Nations women by legalising government policies and organisations which encourage colonialist, patriarchal thinking and discriminatory actions based on gender bias.

The grief experienced by First Nations due to colonisation has been handed down through the generations (Middleton-Moz & Fedrid, 1987), while the forces of poverty and governmental repression have led Aboriginal women to struggle for identity, validation, inclusion and survival. Canadian history has been one in which extreme expressions of racism have led to Native self-destruction. This past forces today's First Nations women to survive in many ways. And while they are enduring social, psychological and spiritual violations, it has been almost impossible to pursue positive action through challenging the social conditions within and outside of the political arena. But First Nations women have found and do recover their voices while guiding others to speak out about the truth of their lives.

Although it is true that social and gender issues affect all women in Canada, Aboriginal women must also endure a historically rooted racism tied to sexism. This oppressive environment makes health issues for Native women and their children a grave concern. In Herbert's 1994 research on First Nations women, she notes that in Canada: Native women have the poorest incomes in the country; they die at a young age, many from violence and suicide; they are over-represented in prisons and many of these women have experienced abuse; only one-fifth of women on-reserve will attain their high school diplomas and many First Nations women will be single parents. These realities correspond to poor health and living environments

on and off reserve, which are not beneficial in any way to either preventing or treating Fetal Alcohol Syndrome. Indeed, because of these problems, First Nations women are even more stigmatised when they do have children who are diagnosed with F.A.S.

### Research

Research conducted on Fetal Alcohol Syndrome in First Nations communities is a contentious and difficult subject. I find it to be an uneasy task to undertake because I feel I must present the complexity of F.A.S. without making it strictly a First Nations "issue." As Philip May (1991) writes:

The attention paid to high rates of fetal alcohol syndrome in a few American Indian communities may have obscured some of the truth about other Indian communities and the prevalence of fetal alcohol effects in the overall population of the United States (p. 239).

The Standing Committee on Health reported to the Canadian Federal Government in 1992 that there is an over-representation of First Nations in studies on F.A.S. in Canada, with a concurrent lack of research on F.A.S. incidence rates in non-Native communities, which may cause stigmatisation (Canada, 1992, December). However, the above-mentioned historical outline and discussion about First Nations women was meant to allow the reader to understand some of the conditions which have forced First Nations to have very particular challenges regarding F.A.S. in this society. The context within which F.A.S. does exist in the First Nations community is important to know, as the disease impacts this population in very specific ways because of historical and cultural discrimination.

Myths and stereotypes, such as First Nations having an inability to metabolise alcohol have no support in the current research (May, 1991), yet these beliefs continue to perpetuate the idea that F.A.S. is a First Nations problem. In fact, May et al. (1982/83) discuss how:

...60 percent of all U.S. women consume some alcohol, while surveys among the Navajo (13-23%) and Plains (50-55%) tribes show that only 13 - 55 per cent of women drink (p.383).

And while it is true that extremely high rates of F.A.S. have been found in studies of First Nations communities in Canada (Robinson, Conry, Conry, 1987), "the studies of Canadian Indians have focused mainly on small communities in high-risk (heavy drinking) areas" (May, 1991; p. 241). At the present time, one cannot compare prevalence rates of F.A.S. in various populations without making the mistake of assuming that F.A.S. research has been comprehensive and that it is not biased. As well, studies have grouped a variety of First Nations communities with each other as homogenous groups, while in fact, the First Nations groups represented in research come from communities that are rural or urban and come from a variety of backgrounds with different social norms, societal problems and community strengths.

Studies on First Nations and F.A.S. must be examined and questioned. One must ask if research techniques are culturally sensitive, as well as gender sensitive and appropriate. Readers must continue to ask what information researchers are trying to find, what are their motives, who are they funded by? For instance, if the bulk of the research finds that the incidence of F.A.S. is higher in lower socio-economic groups, yet all women are susceptible to drinking while pregnant (particularly if they do not have information about F.A.S.), what has happened to the children of the women not in the groups represented by the current research (MacPhee, 1992)? Do these children get diagnosed with this disease, or are First Nations children treated and/or diagnosed differently than other children? There is simply not an adequate amount of information about F.A.S. to know the answers to basic questions about the disease, including the prevalence rates, and, more basically, how F.A.S. occurs, how we can prevent it and how we can intervene effectively when children are diagnosed with F.A.S.

Other factors that play a significant role in F.A.S. research in all communities are the drinking styles, patterns, and norms of various populations. For instance, it should be noted that "sporadic alcohol abuse (heavy binge drinking) causes a greater frequency of mortality and negative effects than does chronic abuse" (May, 1991; p. 239). This kind of research information has a definite impact on how F.A.S. prevention and intervention programs should be conducted in various communities. As well:

In an article that analysed the Canadian studies...Bray and Anderson (1989) stated that a major weakness of the studies was the lack of specification of "a subpopulation at high risk." That is, which particular types of Indians are at high risk for alcohol problems, FAS, and FAE? The inverse of this question is also true: which particular types of Indians are at low risk? (May, 1991; p. 241)

May (1991) goes on to note that there is great variability in F.A.S. rates between different First Nations groups, that First Nations women and their changing roles, as well as behavioural patterns related to drinking also influence F.A.S. prevalence rates. Many other issues such as health, suicide, marriage, death and mortality rates all play a part in the discussion of F.A.S. in First Nations communities (May, 1991). Yet very little research has documented the above issues, nor the historic and environmental issues impacting Native Nations.

In their paper entitled, "Appraisal of the Epidemiology of Fetal Alcohol Syndrome among Canadian Native Peoples" Bray and Anderson (1989) also question research bias in regards to Canadian F.A.S. studies. They question the way that various studies derived population definitions and whether criteria for F.A.S. was applied equally to both Natives and non-Natives, the way in which sample populations were found which may have over-represented First Nations people, that some of the testing and assessment tools were biased against rural children, other confounders affecting the extent of F.A.S. in First Nations children (such as smoking) were not represented in studies, and no groups in non-Native communities were

available for comparison to groups studied in First Nations communities. They warn that caution should be used when talking about the high rates of F.A.S. prevalence in First Nations communities, as there is a definite lack of research in other populations and we must question the way that research is performed in First Nations groups.

Perhaps the documentation most lacking on F.A.S. in the First Nations community is again the connection of systemic problems to First Nations health. Alcohol use in First Nations communities is "rooted in longstanding social injustice, and perpetuated by legislation and economic deprivation..." (Robinson, Armstrong, Moczuk, Loock, 1992; p. 337). Other factors such as poverty, unemployment, education, health, violence, justice system discrimination, racism and sexism all dramatically influence the experience and health of First Nations people in Canada. The B.C. Provincial Health Officer's Annual Report in 1994 recommended that:

Aboriginal communities should be given control over the resources they need to improve the conditions that affect their health status, through augmentation of the trend to self-governance and settlement of land claims. Inequities in health service delivery and community infrastructural support to Aboriginal people should be eliminated, through cooperative efforts of the federal and provincial governments (British Columbia, 1994; p. 21).

The way in which F.A.S. has been viewed and researched, and the solutions to prevention and intervention of this disease are clearly directly related to exploration of systemic issues. It is in this context that the knowledge of First Nations counsellors becomes so valuable, as they will be able to provide special insight into F.A.S., its causes, effective prevention and intervention programs.

First Nations Counsellors - Guides Within The Circle

As the above sections illustrate, F.A.S. is a pertinent issue for First Nations people not because it exists in the Native community, but because it is a preventable disease in great part connected to the Aboriginal community because of the corollary issues of racism, colonisation and social injustice. Systemic issues must be addressed in order to eradicate the disease. Without this structural understanding, inadequate funding, skewed research and biased treatment programs will not help to address the issue of F.A.S. as it exists, for as one can begin to recognise in the literature, F.A.S. continues to be a growing problem in all communities.

Historical systemic problems have critically affected Native health and continue to play out in the First Nations community in many complex ways. Today, in Canada:

There is currently disagreement among Aboriginal groups about the best way to deal with issues such as the prevention of FAS/FAE and NAS and alcohol/drug abuse. It will be a challenge for government to remain open to and respond sensitively and appropriately to the divergent expressions of need by the Aboriginal community (YWCA, 1993; p. 47).

While Aboriginal people tackle the problem of F.A.S., it remains to be seen how governments will in fact respond to such a specific health issue. There also rests a greater problem in health care service for First Nations which stems from federal and provincial jurisdictional issues.

The distinction between Status and non-Status, on-reserve and off-reserve populations appears to lie at the heart of this debate (YWCA, 1993; p. 47).

The effort to provide comprehensive, community-based programs is made extremely difficult because of political definitions of Aboriginal identity resulting in funding discrepancies between First Nations individuals and agencies. This problem then results in First Nations health programs being inadequately funded, or simply non-existent for many communities.



A new perspective needs to be developed in the approach to F.A.S. Society can no longer view it as simply a medical disease, a disease caused by addiction, or a First Nations problem.

Elder Earl Duncan stated at the Winnipeg conference on FAS in 1993:

Today there is an urgent need for change in all health services to people and their children. Government and other non-native groups thought that they knew what was right for Aboriginal people. History tells us that they were quite wrong (Manitoba, 1993; p. 14).

In the B.C. Provincial Health Officer's Annual Report of 1994, it was stated that besides the other factors which may play a part in poor health status:

Loss of place and cultural identity stemming from the European conquest are also important influences. Solutions require addressing these underlying factors. Some Aboriginal communities have begun to make improvements in these conditions that ultimately affect health. This is being achieved through community self-governance, including control of local health services (British Columbia, 1994; p. 21).

An important part of taking control of our health includes having First Nations workers involved in all aspects of the health care system at local, provincial and federal levels, which should include the development of research, education and treatment programs relating to F.A.S. First Nations practitioners dealing with this issue in their communities must provide service at the interpersonal level, but we must also be engaged in self-determination for each Native Nation.

Comprehensive community programs to fight and treat F.A.S. are essential to providing an effective response to this disease. The determinants of this disease are many, and yet they will be specific to a community, to a family and to an individual. Therefore, effective programs should be as multi-faceted and individualised as the community within which they exist. A variety of solutions can and should be developed to fit the needs of the people a program serves. Significant to creating a successful program is the First Nations social service worker. In a report on counselling in the United States, it was noted that:

Traditional American Indian tribal groups have unique perspectives on both the process and theory of counselling and therapy (LaFromboise, 1988). These views differ

considerably from those of the dominant society. Knowledge of and respect for an Indian worldview and value system - which varies according to the client's tribe, level of acculturation, and other personal characteristics - is fundamental not only for creating the trusting counselor-client relationship vital to the helping process but also for defining the counselling style or approach most appropriate for each client (LaFromboise, et al., 1990; p. 629).

The literature supports the training and hiring of First Nations professionals and counsellors who are familiar with the cultural needs of the community extremely important to the overall effectiveness of F.A.S. prevention and treatment programs (Manitoba, 1993; May & Hymbaugh, 1983).

The First Nation professional's understanding and treatment of F.A.S. is invaluable for many reasons. As Nellie Erickson, a nursing co-ordinator at the Cree National Tribal Health Centre in The Pas notes:

...Aboriginal health professionals and educators are really not different from the non-Aboriginal educator and health care provider but one of the things that I would like to suggest is that we come with very special knowledge, just like you recognize that of a nurse who has studied and worked for a long time in intensive care and it is that special knowledge that we would like to be able to share not only with our nursing membership but with all other health professionals (Manitoba, 1993; p. 34).

As there exists in the literature an admitted lack of sensitivity to culture and gender issues, this expertise within the First Nations community can be used to open up discussion about the disease, perhaps leading to innovative ways to treat and prevent F.A.S.

Several programs have indicated that First Nations professionals involved in the health field are important to breaking the cycle of F.A.S. in the Aboriginal community. In 1983, May and Hymbaugh noted that their F.A.S. pilot project included local First Nations individuals on staff who translated materials into the local Navajo language. It was felt that these individuals helped to ensure cultural sensitivity in the program. Masis and May (1991), in their research on

a prevention program in Tuba City, Arizona, discuss how Navajo staff members affected a comprehensive local F.A.S. prevention program.

Another key element in the acceptance of the program, both by the community as a whole and by individual clients, was the status of the program staff members as trusted community residents. Their skills in bridging the gap between the dominant culture and the Navajo culture were indispensable in gaining support by the community as well as the cooperation of pregnant clients. Such community leaders have been called "natural helpers" (Masis & May, 1991; p. 489).

Streissguth, LaDue and Randels (1988) also write that tribal councils and community leaders are an important part of the healing of First Nations. They discuss the importance of community involvement, but also how traditional environments, crafts and skills may play an important part in healing a community.

F.A.S. programs in Canadian First Nations communities may also be made more relevant with the reinforcement of traditional practices and an in-depth understanding about the community in which a professional works. A personal path of healing, rediscovery of pride, recovery from personal trauma, and comprehension of historical Aboriginal oppression are important parts of counselling practised by any healer from the First Nations community. The Red Road, or the path of healing, is a path on which the First Nations person defines their own connection to tradition and the "old ways" (Osenntion & Skonaganleh:ra, 1989). This path is a way of life which often involves the use of traditional medicines and health practices and for some peoples the use of the "wheel of life", or the medicine wheel, which honours the spiritual, emotional, physical and mental parts of our self (Four Worlds Development Project, 1985). These ways are defined by the individual in relation to their own understandings.

Health was traditionally defined by many First Nations as part of the harmonious relation of the Earth, our mother, and the spirit, our grandfather, to the lives of First Nations within a variety of traditions. We celebrated and honoured our health through daily spiritual practices.

Traditional prevention of sickness is reflected in the balance of our self to all things, for all things have spirit. The use of smudging, sweats, fasting, and using whole foods, pure water and sacred medicines, are a combination of traditional health practices which were seen to and do produce a balanced human being (Malloch, 1982).

It is often said that the appropriation and selling of any part of this spiritual way of life denigrates the power that ceremonies and sacred tools have for healing. All things must be used in a good way and with an open heart, or the connection to the Creator and health is lost, which is unfortunately exactly what has happened to First Nations through the many years of colonisation. First Nations health practice is in direct contradiction to the Euro-Canadian ethic of consumerism and bio-medical practicality concerning health issues and service delivery. Meshing these two ways of practising becomes very difficult and raises many ethical questions and concerns. In particular, it forces the First Nations worker to flexibly practice with other Aboriginal people who honour their own traditions, with those who have lost touch with or have chosen not to acknowledge their ancestry, as well as with non-First Nations individuals and groups.

In Marie Anderson's (1993) study on the treatment of alcohol abuse, she notes that the First Nations worker is important to a successful treatment program. She concludes that:

...aboriginal methods and approaches to counselling may contribute significantly to the recovery process of aboriginal clients (p. 78).

First Nations professionals bring a unique insight to their work. Counselling is not necessarily practised in a strict or formal traditional manner, but neither does it necessarily solely rely on formal university education. First Nations counsellors bring their own mix of traditions, methods, understandings, and sensitivity to the way in which F.A.S. is perceived and dealt with in their communities.

At the Vancouver Aboriginal Child and Family Services Society, where I am currently employed, I have recognised that there is a strong current running through the First Nations community which is energising our workers to find new and innovative ways to help their friends and family. I believe this energy was born from a powerful healing force which relies on the collective strength and spirit of Aboriginal peoples. There are many First Nations counsellors trying to help others to find their strong voice inside and they have become guides within the circle of the First Nations community helping the rest of us to health and wholeness.

There can be no doubt that a disease like Fetal Alcohol Syndrome can potentially have a terrible impact on the First Nations people of Canada. This disease affects our children and could result in terrible intergenerational consequences. In fact, in the case of inhalant abuse in the United States, it is being reported that "...it is conceivable that many Mexican American and Native American families and tribes are at risk of being lost forever" (Jasso & Varella, 1992; p. 85). Without successful prevention and intervention efforts, Fetal Alcohol Syndrome cannot be stopped.

But, with more knowledge about the disease, recognition of systemic, gender and cultural issues effecting health practices, dedicated counselling efforts, and effective strategies designed to prevent and treat F.A.S. we will be able to eradicate the disease. At the 1992 FAS/FAE Symposium in Vancouver, an Aboriginal strategy to prevent FAS/FAE noted the following as necessities:

- develop health promotion material appropriate for Aboriginal populations, including funding for videos;
- access to assessments;
- immediate support and treatment services for mothers and families, i.e.:
  - alcohol treatment services,
  - access for all families with children with development problems to available services offered by health, education and social services (Infant Development Programs provided by Provincial health are not available to people living on reserves);

- resources (funding) for special needs education, and
- resources for a national symposium or conference focusing on all Aboriginal peoples in Canada (Canada, 1992, December; p. 71).

Efforts to deal with this disease are growing as we become aware of the needs of the families affected by F.A.S. Most importantly, our children, whatever the circumstance surrounding their lives should be remembered to be valuable, precious and worth all our committed efforts to love and care for them. One way in which to produce information which furthers our understanding of practitioners' interventions regarding F.A.S. and is in keeping with my own need to honour the participants' knowledge as much as possible in this thesis is explained in the next section.

## CHAPTER THREE

### METHODOLOGY

#### A Qualitative Approach

Research can be useful and powerful when it exists within a specific context in relation to other information. The methodology used to gather and analyse data is critical in establishing whether or not information contained in a study is empowering, positive and practical. I wanted this thesis to serve the purpose of providing valuable information which may be used by the research participants and others in order to encourage change and social action. Therefore, I thoughtfully pursued the method for this research through a process of working with and learning about the nature of my inquiry, and my method emerged through and was shaped by my learning.

The methodological route I have chosen is non-experimental. This study explores the experience and words of those participating in this event and does not generate or test theory. The methodological route through which I will explore the participant's words will be qualitative and the data has been gathered in the form of interviews in the field. I employed narrative analysis to explore the participant's voices, using some of their own words to establish themes from which I share the information I received. This particular way of analysing data allows me to understand the First Nations practitioners' practices as the participants experienced them.

There are several reasons I chose to pursue this particular research method. The nature of the inquiry itself helped to form the kind of method I have used, and this process in turn was formed and informed by many theoretical and personal influences. I have been much inspired to write within an emancipatory/empowering research approach, as is discussed by Patti Lather (1991) in her book, Getting Smart: Feminist Research And Pedagogy With/In The Postmodern. Hermeneutic, feminist perspectives and traditions have also influenced my method. And finally,

my own experience as a First Nations woman and an academic, as well as personal and clinical experiences with the participants who originally encouraged this research have also influenced my choice of methodology.

I will now explore this method and my influences in more detail, in order to fully describe the rationale for my approach and the choices that I have made leading to my own particular methodological procedure. I feel that I must mention that this process of choosing and developing a methodology was not linear, nor was it self-evident; it came into being as I formed my inquiry, pilot tested my questions and researched the subject, etc. Therefore, the text in this chapter is written to provide information about the rings of knowledge that helped to build my study, but it cannot capture the true depth and sense of idea-connection that the spiral of the research process motivated.

The focus of this investigation was to hear and represent people's experiences, thus qualitative research seemed an appropriate methodological route to follow. This type of exploration allows the researcher to use discourse and experience as viable data, without the statistical facts and blatant manipulative techniques used in quantitative/experimental research. Among the many ways that qualitative research and methodology can be described, Marshall and Rossman (1989) picture a methodology:

...that entails immersion in the everyday life of the setting chosen for study, that values participants' perspectives on their worlds and seeks to discover those perspectives, that views inquiry as an interactive process between the researcher and the participants, and that is primarily descriptive and relies on people's words as the primary data (p. 11).

With the goal of understanding First Nations practitioner's experiences with First Nations families affected by F.A.S., qualitative research methodology allowed me the opportunity to hear and record the practitioner's own words and wisdom about their experience.



Methodology should represent the purpose of the study and its attending information in a useful and sound way (Marshall & Rossman, 1989). Traditionally, in defending the rationale, or "soundness" of qualitative research, and more precisely in this study a narrative analysis of participant's words and speech, I and other researchers must demonstrate the validity, reliability and objectivity within the report. I will now undertake to examine, explain and justify my choices made around these research underpinnings.

Traditional research at the academy has always been evaluated by the potential of a study to be applicable to other situations, on whether or not it is consistent in its method, that it is "value free" in its approach, and most of all, that it may be replicated in the future (Marshall & Rossman, 1989). In approaching methodology for this particular inquiry, my initial reaction was to strive to fulfil these conventional research obligations, but I soon realised that I would have to strive to redefine these elements of traditional research construction. As Marshall and Rossman (1989) cite of the traditional evaluation tools:

...Lincoln and Guba match these terms to the conventional positivist paradigm-internal validity, external validity, reliability, and objectivity-they then demonstrate how inappropriate these constructs are for naturalistic or qualitative inquiry (p. 145).

Conventional constructs do not work within qualitative inquiry, because they establish rules for research that do not work within a method designed to establish findings that are not strictly quantitative, or measurable. Instead, the authors approach qualitative research by establishing four alternative constructs; credibility, transferability, dependability and confirmability.

In order for the study to be "credible", a researcher must show that "the subject was accurately identified and described" (Marshall & Rossman, 1989; p. 145). And, thus good qualitative research must fully describe the participants in relation to their participation in a study. Furthermore, the validity of the study will therefore be extremely high because the data is

derived from the participants in the study and their own words have been used to explore the data. Marshall and Rossman (1989) suggest the study "will be so embedded with data derived from the setting that it cannot help but be valid" (p. 145). Thus, this research will strive to be credible and valid as it is steeped in the participants, their words and knowledge, and the context from which all information is derived.

To "transfer" the findings of a study to other findings, or connect this study's findings to other research efforts, is more of a problem for this piece of qualitative research, as the report is entirely dependent on a very particular context, time, setting and population sample. Indeed, the strength of this research is that it is particularly rich in validity, but the ability to make relevant the details of the study in relation to other research, "rests more with the investigator who would make that transfer than with the original investigator" (Marshall & Rossman, 1989; p. 145). To try and ensure that this research might be transferred in an empowering way, the context for the research is theoretically grounded in the research subject; F.A.S. and its attending issues, its relation to prevention, intervention, women, the First Nations community, along with a particular focus on cultural and historical context. Transferability has been enhanced within this project through the researcher's careful efforts to document and clearly articulate the research process.

Making sure that this study is "dependable", I account for the ways in which this study was conducted, describe the participants involvement, note changes in the design and method of this research, and describe this researcher's involvement with the research inquiry.

Positivist notions of reliability assume an unchanging universe, where inquiry could, quite logically, be replicated (Marshall & Rossman, 1989; p. 147).

But, I do not intend to try to capture and reveal naked data as it exists in a vacuum, so it can be replicated and "proven". Instead, my own sense of ethics, common sense, and the nature of this research, prescribes that I represent the data as a unique vision and understanding. This

knowledge was shared with me at a specific time and place, for no purpose other than to allow me to be the instrument of transcription, which will in turn, allow others to share in this rich and valuable information.

Lastly, "confirming" how the study was performed ensures that I represent my own insights when interpreting the information I received. I do not attempt to remain objective during this inquiry, but indeed explain in detail my subjective experience as part of the investigation. My own perspectives, knowledge, insights, experience and history influence the way in which I have documented and performed this research. The strength of confirmability within a qualitative project lies within the subjective analysis which "increase[s] the likelihood that she [the researcher] will be able to describe the complex social system being researched" (Marshall & Rossman, 1989; p. 147). In order to ensure confirmability, I document my subjectivity and bias with attention to my critical inquiry of the subject and my own analysis. I also search for all positive and negative connections in the data, I check and recheck data, see that my transcriptions are accurate and my analysis is written with recognition of the participant's voice, and further check my written work and analysis with the participants and my advisor.

Patti Lather (1991) describes qualitative method in a way that is oriented toward emancipation and empowerment. Her focus on evaluation of qualitative research relies on the strength of a project's validity. Lather writes:

Guba and Lincoln argue for analogues to the major principles of orthodox rigor. They state that the minimum requirement for assessing validity in new paradigm research should enlist the techniques of triangulation, reflexivity and member checks (1981). Building on these, I offer a re-conceptualisation of validity appropriate for research that is openly committed to a more just social order (p. 66).

These constructs further confirm the ways in which I have chosen to build and evaluate this research. By triangulating, or using counter and converging patterns in the data, I can make the

information more credible as this process helps to build the strength of each theme I uncover. This is accomplished through the use of quantitative data alongside the qualitative information, as well as being used as part of the process of analysing the data. With reflexivity, I have tried to ceaselessly search out and represent my own perspectives and biases in interpreting the data findings. And, with member checks, I engage the participants in checking the data, as I write and represent it.

In redesigning research constructs and evaluation, Lather (1991) acknowledges the notion of "catalytic validity" (p. 68) which:

...represents the degree to which the research process re-orientes, focuses and energises participants toward knowing reality in order to transform it, a process Friere (1973) terms conscientization (p. 68).

In an attempt to make the research ultimately relevant, purposeful and emancipatory, one should check to ensure that the research is useful to the participants whose experiences are being documented. This ultimate goal makes collaborative research positive and empowering, which always was and continues to be the impetus for pursuing this particular inquiry.

When it was clear that my inquiry would primarily be a qualitative effort, and information would be represented in a textual form, I searched for the best possible way in which I could know and communicate this information. As the majority of work done by counsellors is verbal and in relation to others, it seemed that interviewing would be an excellent method of retrieving information. Crabtree and Miller (1992) note how many health professionals,

...share information in the form of explanatory talk. Whenever two or more gather, they usually seize the opportunity to share experiences, puzzlements, insights, and frustrations (p. 17).

This type of involved sharing seemed to provide a familiar, comfortable and safe way of gathering the information needed for this study.

I then decided to pursue in-depth interviewing with a semi-structured guide (Crabtree & Miller, 1992).

Semistructured interviews are guided, concentrated, focused, and open-ended communication events that are co-created by the investigator and interviewee(s) and occur outside the stream of everyday life. The questions, probes, and prompts are written in the form of a flexible interview guide (Crabtree & Miller, 1992; p. 16).

This type of interview would allow me to gather an abundance of information. And, because "The structure stems from the particular topics to be covered, but it is minimal structure" (Hessler, 1992; p. 148), it would not therefore determine people's answers, but would allow me to provide some direction within the conversations (See Appendix 5).

Ultimately important to decisions made about my methodological route was the population I am working with and their own preferences and style for communicating knowledge. Using stories is clearly acknowledged within the First Nations community as a way in which to value and honour our voices and wisdom. As Lee Maracle (1990) writes in "Oratory: Coming to Theory":

There is a story in every line of theory. The difference between us and European (predominantly white male) scholars is that we admit this, and present theory through story (p. 7).

Maracle then goes on to say:

Our orators know that words governing human direction are sacred, prayerful presentations of the human experience, its direction, and the need for transformation in the human condition which arises from time to time (p. 11).

Story-telling connects critical understandings about the relationship between self, culture and history that are important for this researcher to acknowledge in terms of honouring the voice of the participants.

Furthermore, in an article entitled, "Western Scientific Colonialism And The Re-emergence of Native Science" by Pam Colorado and Don Collins (1987), story-telling is

documented as a crucial part of "Native Science" (p. 60). In living within the cycle of all things, they describe a new paradigm for research within First Nations science as a holistic and spiritual process.

Seeking truth and coming to knowledge necessitates studying the cycles, relationships and connections between things (p. 58).

In other words, Native science considers the process and cycle of living as sacred and through exploration of feelings, using history as a tool, by praying and acknowledging relatedness, we become balanced with the universe. And, we choose our voices and stories as ways in which we express and unite our understanding and reality.

The sense of connectedness for myself and others to this research is essential in making this process an emancipatory effort. Qualitative research is exciting because it allows the researcher to focus on the experience of people. It does not rely on statistics, but on the thoughts, ideas, and richness of experience. This form of research can be rigorous and valuable, when it is evaluated with constructs that fairly critique its presentation. As well, it allows the use of common procedures like interviewing in the field to be used as data gathering tools. With researcher and reader conscientiousness, with a view to making information valuable and useful, qualitative studies can become dynamic tools of freedom.

### Theoretical Influences

An exploration of the many theoretical influences which guide my work and writing are outlined in this section. What has perhaps most influenced my methodology is Patti Lather's (1991) concern with "Research as Praxis" (p. 50). This direction in social science proposes to develop research efforts that interactively involve theory and practice to develop empowering research which helps to produce a more just society. This new "postpositivist" (Lather, 1991; p. 50) era in research construction calls for research to exist in a contextual environment in which it

is productive and socially conscious. A commitment to producing such research means working hard to engage and experience the understanding of others, but it also means a greater possibility of social transformation.

Mishler (1986) also notes that by making sure research is written in context, with the participants as partners in the research effort, and with a distinct conception about how the research will be used, these:

...proposed transformations in research practice are intended to empower respondents by facilitating their efforts to learn and act (p. 135).

This conception of research and the effort that is made to include the participant as a force within the learning effort is a way to enable and encourage social transformation. And, the goal of this research is to create a space within which interactive dialogue allows our lived experience to generate knowledge that further emancipates us from discrimination and oppression.

Hermeneutics is a philosophical tradition that provides a way through which research may be understood and interpreted. It does not propose a particular type of methodology, or rules about analysis of data. Hermeneutics is an approach to research that tries to understand individual experience within the larger social sphere. This is part of the philosophical underpinning through which I engaged participants in this research. A hermeneutic approach includes such practices as immersing oneself in the data, including one's own biases and values as an important part of the research event, entering into active dialogue with participants, as well as watching and including the larger historical and cultural context as background for understanding information (Addison, 1992). The assumptions and practices within this approach allowed me to further explore a methodology that I felt was compatible to my own beliefs and vision about the possibilities of interactive and empowering social work research.

Within myself, Feminism is a profound and deep-rooted perspective that has also influenced the way I have approached this research process. Feminism is a wide-ranging and challenging philosophical orientation to describe. In telling how feminism influences my work, I could engage in discussions about Postmodern Feminism, Feminism in relation to politics and social work, or Feminism and culture. Instead, I wish only to say that as a perspective, Feminism allows me to envision this piece of research as a process through which my own senses are valuable research tools. I work with the assumptions that this research is as non-exploitative as possible, that I include my colleagues as participants in this exchange, that this research exists within a particular socio-political environment and cultural context, and that hopefully, this written knowledge encourages equity and social change (Strauss & Corbin, 1990).

Finally, the very essence of this research is born from my own being and heritage. I am, among many things, a mixed-heritage First Nations woman and a mother. I have worked in my community in many ways and see this project as a new part of the process of learning, creating and working within my community. My own history includes travelling through a variety of other nations, working overseas, spending a great deal of time at University exploring other people's words and knowledge, as well as working for approximately 10 years in the social services field.

My pride in and responsibility to my community deepens with my life work and journey. In engaging in this research, I hope to further my own understanding, but I also wish to build a path to new voices that everyone may get a chance to hear and feel. There is no keener sense of hope and joy that I have experienced in the course of my life, than when my daughter was born. This experience has further nurtured my desire to connect with the First Nations community in a



way that is healthy and productive. It is pride, strength and promise that I see in my daughter's eyes and so it should be apparent in all our First Nations children.

### Participants

The participants for this study are all First Nations counsellors who live and work in British Columbia. These counsellors were contacted through introductory letters mailed out to the community through my own efforts, as well as being passed out at conferences regarding F.A.S. The counsellors who replied were all interested in and had been working with the issue of F.A.S. Though their workplaces varied greatly, as is discussed in Chapter Four, the “Interview Results”, the participants’ interest in this research came from personal experiences and work efforts with families and children affected by F.A.S.

I asked for some demographic information on the participants to help myself and the reader understand more about the voices that speak throughout this paper (Table 1). The counsellors are originally from various parts of the country, although 4 of the 6 participants now live in Vancouver, while two others live outside the city. In total, four women and two men participated in the research. Their ages range from 30 to 47 years, and they hold a variety of beliefs, traditions and schooling in the social services field. Four of the participants noted that they were status First Nations, one answered as non-status, while one participant identified as Metis. Two of the participants identified themselves as divorced, two as married, and two as living with partners. They hold a variety of feelings and connectedness to First Nations culture, their families and their heritage.

### Recruitment and Selection

My criteria for choosing these counsellors rested on a few simple needs for this project. I first of all asked "counsellors" about their experiences. When I use the term "counsellor", I mean those people that serve the public in the social services field. These people could be therapists, social workers, family support workers, court workers and para-professional counsellors. Most of these individuals work on the "front lines", meaning that they work face-to-face with families, providing services that are identified at their agencies through self-referrals, through Ministry of Social Services referrals, or through referrals from other agencies who have identified issues in the family.

Table 1: Profile of Participants

GENDER:	Female	4
	Male	2
<hr/>		
AGE:	30 - 35	1
	36 - 39	2
	40 - 45	2
	46 - 50	1
<hr/>		
FORMAL EDUCATION:		
	Certificate (Social Services)	1
	Diplomas	1
	(Social Services/Criminology)	
	Some General University studies	1
	(Under 1 year)	
	2+ years University	2
	(General Academic courses)	
	Bachelor Degree (Nursing)	1
<hr/>		
YEARS OF WORKEXPERIENCE IN THE FIRST NATIONS COMMUNITY:		
	1 - 5 years	1
	6 - 10 years	4
	11 - 15 years	1
<hr/>		
INVOLVEMENT IN ANY TRADITIONAL FIRST NATIONS PRACTICES:		
	Yes	6
	No	0
<hr/>		
TRADITIONAL PRACTICES AS DEFINED BY PARTICIPANTS (No particular order):		
Sweats, talking circles, Native Pentecostal Church, daily smudge, healing circles, medicine wheels, pipe ceremonies, personal practices, art (beading, ribbon work, quilt art), hunting, fishing, making snowshoes, train horses, music makers, and advocacy.		

I chose to include only First Nations workers in this research. This decision came from my own wish to hear and document the wisdom from colleagues who I know, but whose wisdom I did not read in the research literature. I am a counsellor in the First Nations community and therefore know potential participants through familial, social and community circles. My sample was a “purposive or judgmental sampling” of individuals (Rubbin & Babbie, 1989; p.229). I particularly wanted to hear what First Nations counsellors had to offer in terms of strategies to help the families who are dealing with Fetal Alcohol Syndrome. Therefore, because of my “...own knowledge of the population, its elements, and the nature of [my] research aims..” (Rubin & Babbie, 1989; p. 229), I chose the target respondent sample. I felt it important to look at what First Nations practitioners do and how we deal with F.A.S. in our own community. I then decided that the participants would be counsellors with some knowledge about Fetal Alcohol Syndrome and experience working with families dealing with this disease.

I felt that the viewpoint that First Nations counsellors would have about their own community would bring special insight to the overall understanding about F.A.S. In the process of designing my research questions, I asked workers to talk about their skills, techniques and experiences with families, but also their personal history. This research becomes vital and alive because it is connected to places and people; the experience is not taken out of context, but I have placed it within an environment that exists because of the participant's lives and work. The participants themselves describe who they are and what they do in relation to the topic discussed. This is the story of a small community of vital and precious experience described by people who committed to this research in order to further a common goal of educating others.

Although I am part of the First Nations social services community, I did not necessarily know the participants before our meeting for this research. Participants were contacted initially

through an introductory letter describing the research, its purpose and the interview process (Appendix 3). Once those individuals replied to me by phone or letter saying they were interested in the research, I then met with them to discuss any questions they may have had regarding confidentiality and how they wanted to be represented in the research. Over the phone, or in person, I further explained to the potential participant the research process we would be engaged in. After the interviews, each individual was thanked for their interest and participation in this project, and a copy of the final paper was promised to every individual who wanted to receive one.

I explained to the participants that the interviews would be conducted at their convenience, in a place of their choice; at my office, their office, my home, or other neutral place. I described the time commitment involved (1 - 2 hours), that we could have breaks and also that there may be feelings that would come up that we would debrief as needed. There are some tools needed for the interviews such as an audio-taped recording of their voices and I explained they would be transcribed so that I could make sure I had a true copy of everything they had said during the interviews. This process would need their permission and a consent form would need to be signed by them (Appendix 4).

Some of the practitioners would also need agency consent forms (Appendix 2) signed to be able to participate in the research, and these were provided with agency introduction letters (Appendix 1) to their supervisors. I talked about the interview and offered them my research questions at our initial meeting, or at the interview, if they wished to see them (Appendix 5). Finally, I discussed how their perception of the interviews and their feedback after my initial description of themes found throughout the interviews, were vital to the research project itself. Practitioners were notified by a final letter (Appendix 7) attached to the results chapter that the

research was almost complete and that I would like to hear their feedback on the “Interview results” when they had a chance to read the chapter.

I chose to hear stories from six counsellors, as I felt that this number of interviews seemed to allow me the advantage of hearing people from a variety of perspectives and work placements, without hampering my ability to process a vast amount of information through narrative analysis techniques. The interviews could be in-depth and more time could be devoted to the individual participant’s needs during the interviews. It also took time to find the participants and then collect information from them, as there exists a lack of agencies, programs and First Nations workers who serve First Nations families who have members that are affected by F.A.S. Those counsellors that participated did so with overloaded time schedules and simply helped with this research because of their personal commitment to improvements in this field.

#### Method Pilot Study

I originally conducted two interviews over a one month period as part of an assignment for my M.S.W. research, from this endeavour I changed some of my original questions and my interview procedure. I initially contacted participants for interviews after they had phoned me regarding the introductory letter I had sent them. I arranged a time for the interview and proceeded to meet the two participants, at their convenience, to tape the interview. When the interviews were over I told them I would be in touch with them to hear their feedback at a later date. I later phoned these two pilot study participants and told them of several changes to the interview process, which they agreed would make the interview smoother.

First, I felt that the participants needed to have more information regarding confidentiality, the research process and their participation in that process, before we actually started the interviews. I included further information regarding the research project into my

initial meetings with participants. I also felt it would be more effective to give the participants a copy of the research questions, along with the confidentiality form prior to the actual interview, which would allow the participants time for more questions about the process before we started the interviews. This could not be realised with all the participants, as often I had to meet and interview the counsellors in one day due to time restraints. Another realisation included finding a way to appropriately thank the individuals for their participation and I decided to offer a copy of the thesis to each of those participants who had helped with the study.

In further researching my methodology, I also decided that I needed to involve the participants more fully in the process of writing the research. Therefore, I decided to offer the participants their own copy of the interview results to read in order to help me with my accuracy, and so that I would not make mistakes in interpreting their words. This part of the process was particularly important, as I wanted all the input from the participants to be truthfully represented in the final report. To be true to my methodological framework, I had to make sure that the counsellors' words, ideas and experience were documented and not strictly my own subjective opinions about what the data meant.

I also realised that many personal feelings came up for the counsellors regarding their experiences growing up, their families, and their work. These issues were deep and troubling for some of the participants. I planned to allow time for a debriefing session at the end of each interview, in order to provide a space for the participant to feel their feelings, as well as to allow them time to gather and focus their thoughts and emotions about these issues. This pilot study was part of the process of gathering information about the topic, but was also informative in helping me to learn how to be a better interviewer. In effect, it was the participants themselves who focused my energy into striving to produce a document representative of the interview

experience. It was indeed the participant's voices that allowed me to adjust my methodology and procedures to better represent and engage in the experience of research.

### Thesis Interviews

The interview process with each of the participants was a completely unique experience. Each of the counsellor's own feelings, ideas, and sense of their work with F.A.S. provided me with exciting new understandings about what First Nation practitioners offer their clients. I looked towards making the interviews an opportunity for each worker to engage in the kind of discussion that allowed them to discover one of the "empowering approaches to generating knowledge" (Lather, 1991; p. 51). For research is a powerful tool that can inspire profound social change, if only the tool is used in the right way. I wanted the participants to be able to speak freely about their experience, knowing that this research would be of value because of their special voice and knowledge.

Each of the participants let me know where and when the interview could take place. For four of the participants, their workplace, or mine, was fine. One interview was held in a restaurant and one interview was held at the student union building at U.B.C. The participants often read the questions before we started, consent forms were signed, and I turned on the tape recorder with the participant's knowledge. Interviews ranged from 45 minutes to 2 hours. Time was often a consideration for those workers who had other work duties to attend to during the interview day. Breaks were discussed, although none of the participants chose to break during the interview.

Some discussion occurred regarding ideas that the participants mentioned. I would ask for meanings and or further clarification of their thoughts. Although there were four interview questions, the participants had much they wanted to discuss about their field and the work they



engaged in with their clients. Also, many of the participants experienced a wide range of emotion throughout the interviews, which is more fully discussed in chapter four.

The interviews started with discussion of personal experiences and how each individual came to be working in this field. We then looked at the way that each worker felt F.A.S. impacted their community. This area often lead participants to discuss their wisdom regarding conventional services offered to First Nations families and how they felt that this was not producing positive, long-term changes for their communities. The practitioners were also asked to talk about their experiences in counselling, what they offer to clients and what is important to know about First Nations families affected by F.A.S. The connection of historical inequities and present day living conditions for First Nations in Canada were discussed by all the practitioners at this point. Finally, when discussing their own practices, many of the workers passionately recounted their own work styles and challenges.

If it was appropriate, I asked the counsellor at the end of the interview if they would like to spend more time to discuss any feelings that had arisen for them. Half the counsellors took some time to talk about their feelings, while the other half felt they were fine and needed no time to debrief. Debriefing was generally a time to acknowledge the emotional investment in the counselling work. I offered to send the participant a copy of the final chapter regarding the information that they offered. I also discussed how the information each participant had given me would be used and analysed, and that a pseudonym could be used for the participant, or their name would be used if they wished. Three of the participants chose the pseudonyms Darel, Paul and Lane, while the other participants chose to have their own names used in the research. These participants were Laura Clement, Lizabeth Hall and Carol Hoof.

Processing/Analysis of Data

With a view to working as a "field researcher" (Marshall & Rossman, 1989; p. 14), interviewing participants and recording their words, I now had decisions to make about how I would analyse this information. As I discussed in the first part of this chapter, my analysis of the data that I had gathered had to be handled in a way that was consistent with my values and overall methodological framework. I felt I first had to decide what the purpose was in searching for and elucidating the information I was seeking. Indeed, the fact that I am First Nations and a mother, that I have dealt with F.A.S. and its devastating effects in my employment at the Vancouver Aboriginal Child and Family Services Society, and finally, because I have discussed this disease many times with my colleagues, I wanted to research this topic. This is my first and overriding bias in this research, I am connected to the topic and therefore it is personal. There was also little research in this particular topic area, therefore my research was clearly exploratory.

As the purpose of this research was to look at, explore and document a particular experience, I did not want to create or elaborate on theory, or even explain the data strictly in terms of my own understanding about its relation to other studies in the field. I therefore chose narrative analysis to process the data, as it allowed me enough flexibility to uncover information, while limiting my influence as much as possible on the interpretation of the data. I merely wanted to be able to allow the voices of my colleagues to speak their own knowledge.

I followed Patton's (1990) discussion of "Inductive Analysis" (p. 390) as my base for analysing the data from the participants.

What people actually say and the descriptions of events observed remain the essence of qualitative inquiry. The analytical process is meant to organise and elucidate telling the story of the data (Patton, 1990; p. 392-393).

This orientation to analysis of data seemed respectful and honouring of the participants' own wisdom, while allowing me to find important understandings within the data.

Inductive analysis means that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis (Patton, 1990; p. 390).

This generation of themes and patterns does not insist on over-analysing the data, but finding those categories and themes that are salient and provocative.

To further refine this form of analysis, I chose to look at category generation which is formed from the words and ideas of the participants themselves, allowing me to build themes and then frameworks which are also the product of the participants' sharing. These "typologies" (Patton, 1990; p. 393) allow one to describe the experiences through the participant's voice, which also helps to encourage feedback from the participants, as their familiar language has been used in the document.

Patton (1990) describes patterns being turned into useful categories through looking for data that seems to fit together, as well as noting irregularities that occur in the data. Categories are prioritised for their:

...salience, credibility, uniqueness, heuristic value, feasibility, special interests, and materiality of the classification schemes. Finally, the category system or set of categories are tested for completeness (Patton, 1990; p. 403-404).

These categories will then be placed into themes that represent the major insights into the research inquiry, as the researcher finds them and as the participants agree they are representative. This process of searching through and classifying the data is ongoing, constant and intense.

Crabtree and Miller (1992) discuss this style of analysing data as "the editing style" (p. 20). They conceive of this process as being:

...much like an editor searching for meaningful segments, cutting, pasting, and rearranging until the reduced summary reveals the interpretive truth in the text (p. 20).

They, too, suggest finding ideas within the transcriptions of data that are particularly meaningful, then sorting these out into patterns and themes. And, again, they summarise this data analysis technique as being a cycle in which one works until the themes have emerged and there is no more data to discover or search through.

In Mishler's (1986) in-depth look at interview narrative analysis, he notes that of particular importance in research is the relationship that occurs between the participant and the researcher. This relationship must be represented in the documentation of the research. Mishler (1986) suggests that researchers approach narrative-analytic methods as:

...studies of interviews as forms of discourse, that is, as speech events whose structure and meaning is jointly produced by interviewers and interviewees (p. 105).

As well, the orientation of the researcher should be clearly defined, in order to allow the reader to understand the perspective with which the researcher has approached their work.

I began analysis of the data by listening to the audio-taped interviews, writing down words and/or ideas that seemed to come up often, or that stood out from the rest of the data. All of the audio-tapes were transcribed and I worked with each of the transcriptions, again looking for words and/or ideas that seemed salient, or that were unique in their expression. Once I had written notes on the transcripts themselves, I wrote out on sheets of paper the words and/or ideas (from all the participants) that I had listened to and tacked them to a cork board. I then began the process of moving the words/ideas around to see if any fit together. When categories began to form, I used the ideas and some of the words of the participants to name themes and then sub-themes. These themes were then discussed with others, so that I could present them in a way that was clear and made sense.

The participants were sent a copy of the fourth chapter discussing the themes and sub-themes I had found in their words. Attached to the "Constructions" was a final letter to all the participants (Appendix 6) and a short form survey for demographic information (Appendix 7) for those who hadn't received it before the interview. Then I followed this action by phoning each of the participants to discuss their feelings about the chapter. One of the participants found that she had enjoyed the chapter very much and carried it with her to review the words during the day. Two of the participants had quickly read the chapter over and did not have any feedback. One counsellor sent back his survey form, but I could not connect with this participant to discuss his feedback.

The feedback I received was thoughtful and thought-provoking. Two of the counsellors had a lot of feedback to share. One participant sent me a letter in the mail, her feedback discussed feelings that arose while reading her own words and she noted an error in my perception regarding her family history that was written into the chapter. I promptly changed this information. The other participant who had lots of ideas about the research, read her comments to me over the phone. Her ideas ranged from thoughts that occurred to her afterwards about the subject of F.A.S., the importance of styles of learning for specific groups of people, the difficulty of working in rural communities with families affected by F.A.S., the importance of F.A.S. diagnosis, the political differences between Metis and Status First Nations in regards to F.A.S. treatment, and how life experience is an important pre-requisite for working effectively in the First Nations community.

I perceived my own participation in this research to be that of providing a way in which the voices of the counsellors could be accessed through research. As Strauss and Corbin (1990) note, there are actually three participant groups involved in the research; the counsellors, the

researcher and the reader of the research. My methodological framework and analytical design attempts to reveal the participant voices while acknowledging my own bias and input. And, hopefully this project engages you, the reader, in a way that is conducive to furthering the effort of social change by shifting the boundaries which keep First Nations voices silenced.

### Limitations and Strengths of the Study

This research is limited by the boundaries of the words as they exist on the page, by the interpretation that I have placed on the participant's experiences, and by reducing the "wholeness" of the interviews into pieces subjectively cut into themes. No amount of description regarding emotion can ever relay the effect of the process of participating in this study, for myself and for the practitioners. I engaged in the research with hopes only that the knowledge of the practitioner would become evident for others, but found myself much more affected on a profoundly personal level by the struggles which my peers faced. This experience is very difficult to retell to the reader of this research, perhaps denying them the full impact of the information shared in this study.

It has also been very difficult to form the knowledge gleaned from the interviews into themes using a subjective decision-making process. I have struggled for long periods of time with the definition of words used as the theme headings, as well as with the ways in which the sub-themes were connected to the main themes. Each connection, definition and decision was a process of struggling to construct a presentation true to the participant's understandings and my own feminist ethic and principles.

Finally, reducing the knowledge of the participants into themes, reduces the ability for the reader to see the "wholeness" of all the information. What I subjectively consider to be of importance may not be of the same import to another, while conversely, what is missing from the

study could have been of interest to other readers. Though these decisions are difficult to make, there is often the feeling amongst those engaged in the process of research that one could attend to, debate and discuss their newly learned information for a very long period of time, while coming to many or no concrete conclusions.

Other limitations in this study might include the research method, the bias in sample, the limitation of six participants and the interview questions. The qualitative method, bias in sample and the small sample size do not allow for the information to be inferred to the general population. Although this was not the intention of the research, the knowledge represented in this project cannot represent the understandings of all First Nations counsellors. "Purposive" sampling (Rubbin & Babbie, 1989; p. 229) also leads to sampling bias and those people who participated in the research obviously felt some level of comfort discussing their experience, which leaves out a large number of First Nations counsellors who did not participate for reasons unknown. The interview questions were also broad and open-ended, which allowed for some of the participants to "wander" as they talked about their ideas. This could sometimes make it difficult to bring the participant back into the present research effort.

Conversely, a great strength of the research is the way in which such rich information can be placed into a format which others can read and share. The ability to take the words and ideas of others and place it into a format where many students, practitioners and others can learn about a certain experience is exciting. Information can be used to create great changes in the ways that we plan policy, programs and practice our professions. This work is valuable not only because of it's uniqueness, but also in and of itself is made powerful due to the strong messages of the participants.

In a positive way, the qualitative methodology allowed for expression and exploration of ideas that strictly quantitative information could not allow. As well, involvement of the participants in the final draft of the interview chapter made the process more of a collaborative effort for all concerned. And, conducting the study in a way that is respectfully honouring the voices of those involved allows each of the participants to experience research in an emancipatory, empowering way and not as an effort to strip people of their knowledge or ideas.

Another strength of the research is the fact that it is a process and not simply a means to an end. The actual struggle through interpreting the data allows me to become more fully aware of ideas, knowledge, and how as practitioners we express ourselves. As Strauss & Corbin (1990) discuss, "the feminist researcher is likely to describe the actual research process as a lived experience" (p. 258). In the truest sense, the research brings change to both myself as a researcher and social worker, as well as to the participants of the research. Each of us has seen our knowledge shared in a way not available prior to this project and that is the essence of social change and research in action...making a difference in our collective and individual experience which is discussed in detail in the next chapter.



## CHAPTER FOUR

### CONSTRUCTIONS

I have chosen to call this chapter “Constructions” to reflect the nature and process inherent in this piece of qualitative research. As Patricia Anne Rodney (1997) notes in her dissertation:

“Results” implies that there was something essential or objective (Bernstein, 1983) to discover - a positivist term that is incongruent with the qualitative and feminist theoretical perspectives informing this study. Thus, I use the term “constructions” instead of results, which acknowledges that what I arrived at in my study was something that was constructed between myself and the research participants (p. 13).

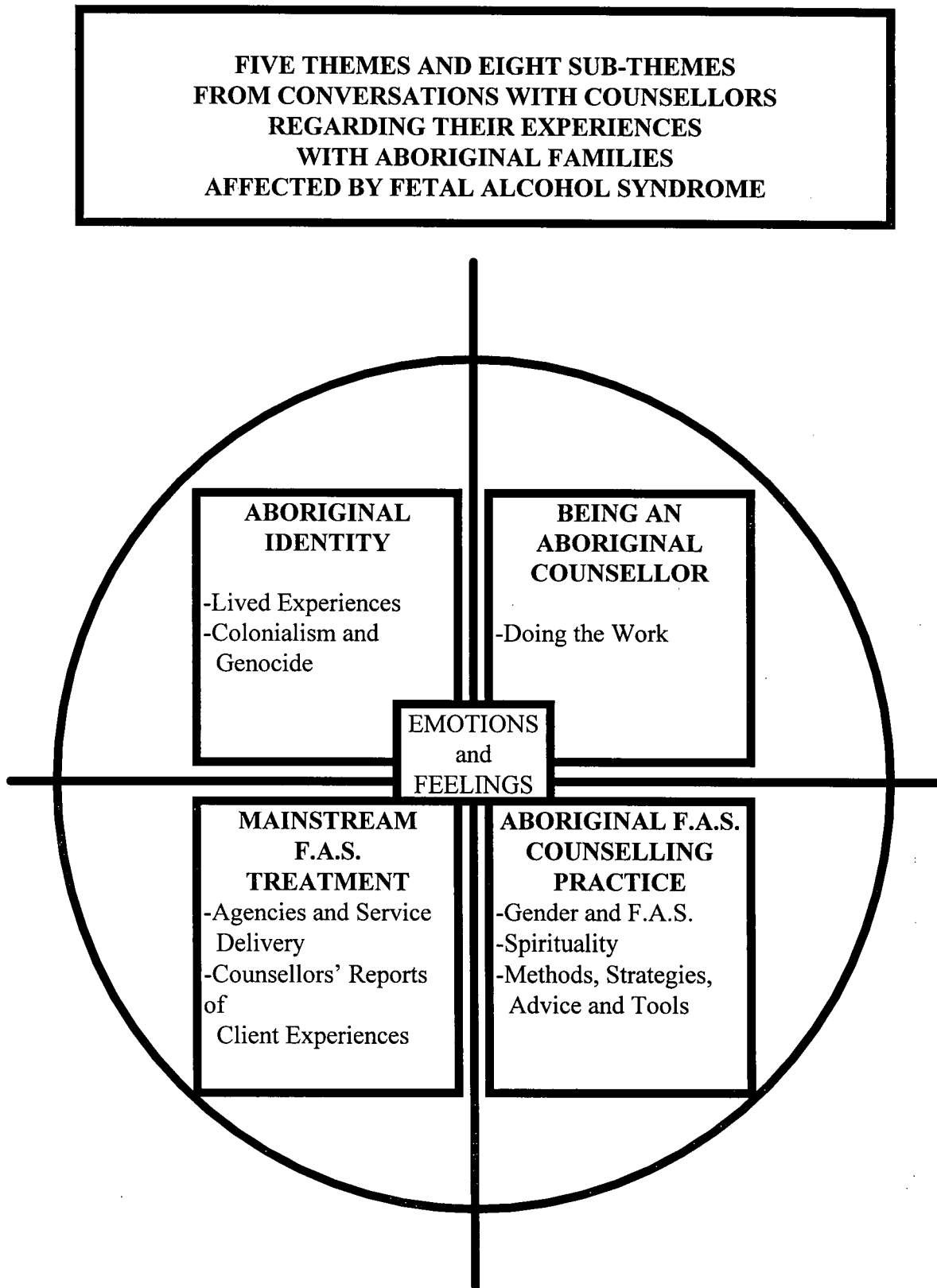
The effort to understand Aboriginal counsellors’ service provision was truly a paper built by the participants and the researcher together.

The work in this study is a result of the gift given by six Aboriginal counsellors who shared with me some insight on their personal lives and professional experiences. In discussing Fetal Alcohol Syndrome in the Aboriginal community, I found four themes prominently arose in the interviews. These were: Aboriginal Identity, Being an Aboriginal Counsellor, Mainstream F.A.S. Treatment, and Aboriginal F.A.S. Counselling Practice and Emotions and Feelings. Sub-themes within the larger themes are also discussed. The themes and sub-themes can be seen in Diagram 1. Individually, each theme develops understanding regarding the Aboriginal counselling experience documented in this study, but it is important to note that the themes are also interrelated and must be read in totality to form a whole picture of the information received during this project.

#### Aboriginal Identity

Each counsellor talked about how important Aboriginal self-identity was to their lives and work. It is important to note that many researchers refer to First Nations self-identity

Figure 1: Guides Within The Circle



stemming from what Frideres (1988) refers to as "a unique culture - one under siege" (p. 279). First Nations have experienced their Canadian Aboriginal identity as associated with incredible turmoil, poverty, discrimination and oppression; therefore realizing a positive self-identity for First Nations today is difficult. Self-identity is an area of great struggle for every individual as well as for First Nations communities. For many First Nations, self-identity is affected by the experience of discrimination, intergenerational self-medication and repeated attempts by governments and individuals to assimilate and eliminate Aboriginal people.

Falconer and Swift (1983) note that the term "Native people refers to all people who, as a matter of self-identity, trace their ancestry in North America to time immemorial" (p. 181). The Metis and Inuit are also officially recognized as distinctive Aboriginal people as is defined in The Constitution Act, 1982 (Canada, 1993). Definitions regarding Aboriginal ancestry have come to be both political and personal, but the definitions given by the counsellors regarding their identities came distinctively from their own private life and experience.

Aboriginal identity, struggling with it, integrating it, understanding and accepting it, was on the minds of all the participants. Concern regarding the knowing of one's roots was evident in each participant's recounting of their past. And, each person related how self-identity as an Aboriginal person played an extremely important part in their life and work choices. Identity, belonging, understanding culture, acceptance, approval and even survival were words at the core of the conversations regarding self-identity. Not only was this topic extremely important to all participants, but it was accepted by most that the struggle for self-identity was what forced them to be strong and effectively do the work they now engage in with their clients.

### Lived Experiences

Participants talked about identification and how it was associated with belonging and/or feeling apart from the rest of society, their families and friends. Darel recalls being the “token Indian at work...” and Laura discusses how she felt isolated from the rest of society because of the physical distance between her family and the rest of her small community.

...my father had some really bad experiences as a child, some very, very abusive situations and he tended to be very isolated from the rest of society. I mean really isolated, we didn't have power 'till I was 16 years old, uhm, we lived in very isolated areas... (Laura).

Lane notes how confused she was about her identity and how she felt, in her words, being an “Indian”. Coming to know past, roots and history is what most participants described as allowing them to regain a sense of balance regarding self-identity and uncovering the roots of their pride.

All of the participants discussed finding out about their roots as they grew older and how that helped to solidify their self-identity. Laura discusses how she learned about the “old ways”, while Paul notes that finding First Nations spiritual practices really helped him to reclaim his sense of self. Lizabeth recalled that her family values regarding knowing yourself, and challenging fears and childhood pain is what allowed her to be strong in her own self-identity.

...what I did get was that connection, you know to who I am, people could call me anything they wanted under the sun when I was ten years old, didn't give a shit, call me an Indian, call me a squaw, it didn't matter because I knew who I was...(Lizabeth).

All the participants talked about how knowing the self meant knowing how to appreciate one's own unique cultural experience that made these individuals, as First Nations, different from other people. More than this, they all discussed how they came to understand that their differences made their self-identities rich and strong.

Lived experiences and shared strengths for all workers included recounting family interactions and memories. The participants described their own childhood environments, which included for all of the counsellors some encounter in their communities with drugs, alcohol, violence and abuse. Some workers remembered their residential school experience, social services involvement in their own families, and other meetings with more subtle systemic and personal discrimination. They discussed their educational backgrounds and other learning, mentioning their current workplaces and family situations. Each participant also talked about their resilience, self-discovery and hope.

All six of the counsellors identified experiencing some turmoil in their families as they grew up. Home environments were described as posing difficulties for the counsellors, and although there were other times and stories of joy expressed by the workers, all six of the counsellors experienced and/or witnessed serious, often life-changing events. Examples of these events include experience with extreme violence, sexual abuse, rapes, substance abuse, and isolation. Each of the participants discussed their personal experiences of prejudice which they felt had affected their home environments. All of the workers witnessed alcohol abuse by their relatives and/or in their communities as they were growing up. As well, memories of confusion and anger tainted all the workers' childhood stories.

Due to the extreme situations which he had to face as a child, Darel described himself as "a maniac...I didn't care". He also related how "...my mother, she drank a lot, she died as a result of alcohol." His actions became more erratic as he grew older, although he did finish his high school education. He notes that the learning from his Elders is what really helped him through his hardest times. Darel discusses how the Elders forced him to stop talking in their

presence and to just listen while he was around them. He relates that it is this loving guidance that influenced him to help others through counselling.

Reports of residential school and terrible isolation in childhood were reported by two of the workers. Laura and Darel note how different the children were who went to residential school. And, at least three of the counsellors discussed their family involvement with social services and the apprehension of First Nations children. Darel talks about his sisters being “taken by social services” and put up for adoption.

...And then, ah, sort of welfare people came from the Department of Indian Affairs came up to the ranch and told my mother...said, “You either get them out to school, or we take them away and that we adopt them out”, and so as a result she told me I give you a real big ice cream and then we’re going down to the school and you’ll be going to school here for a while...(Darel).

And, Laura recounted meeting her peers who had spent their formative years in residential school, “...the adults I met had changed, something was wrong...” Indeed, finding out what was wrong was what encouraged Laura to work in the counselling field in the First Nations community.

There were, however, even more subtle discriminations against these First Nations counsellors than the aforementioned blatant examples of traumatic childhood experiences. Some noted simply that there was an implicit exclusion of their families through silence in the community about their very presence, or they reflected on their encounters with individuals who carried popular “romantic” notions about “Indian culture”, such as Lane discusses about her long black hair. Lane was so ashamed of herself because of the feelings she carried regarding her life experience, when asked if she was an Indian, she cut off her hair as she felt that this marked her “difference.”

...when I was a teen growing up, my hair was really long, I cut it...really short. And, when I was, when I had really long hair people were always saying...”Are you Indian?”  
...when I cut it no one ever asked.

So humiliated was Lane at being “noticed” that she resisted being identified as First Nations through drastic action by altering her appearance.

Carol related another story of, as she put it, “subliminal oppressions raised in a white community”. Carol was adopted into a “white” family. She grew up in this family with the expectations that she would choose success in terms of the standards of the society into which she had been adopted. She was made well aware that there were two kinds of Aboriginals, those who succeed through assimilation and adaptation and those who end up on skid row. Her own feeling was that if she did not conform to the standards set before her, there was no in-between, she would simply fail. She informed this interviewer that at times this expectation still manages to cloud her work ethic and professional demeanor.

...so there was always this sense of feeling that I was never going to do, I was never going to uhm, an expectation that I had to be perfect and I was never going to match that...and, it's only been recently, in the last five to ten years that I realize it's someone else's expectation of me...

Carol discussed how relearning her history and connecting with her birth family has changed her old expectations, but that her childhood teachings have been difficult to overcome.

Paul describes how his own childhood was painful. His move from one part of town to another allowed him to see how his own people were discriminated against by virtue of the different treatment he received living on the “white” side of town, as opposed to the First Nations inner-city community. His own story tells how his experience with the Catholic church through his childhood still informs the inner feeling that the practice of First Nations spirituality is somehow “wrong”. His newfound spiritual practices are sometimes difficult to reconcile with the teachings he received regarding the Catholic way of life. He believes that his childhood was, as he mentioned “not healthy”:

...I think when it first started to appear to me, was that I saw, ah, I saw the little Indian boy in the place that I've worked, alone...and there's something in there about who I am, who I was, and uh, the hurts and uh, recognizing that the anger still comes back and in a sense, uh, huh (sigh), just ah, kids being hurt...and not growing up in, in a healthy way...

He currently continues to focus his energy on deepening his spiritual understanding and practices through First Nations teachings.

Good memories came through stories of grandmothers, aunts, uncles, mothers and fathers who treated the participants well and with love. Many of the counsellors shared their experiences of sitting and listening to their Elders. Some counsellors remembered spending time outside with their families fishing and hunting. In fact, two of the women talked specifically about their strong feelings for their grandmothers. Lizabeth and Laura saw these women as being important teachers. Lizabeth's father had died when she was quite young and she felt she had been treated in a very distinctive way by other family members because of this situation. She also had not ever met one of her grandmothers, the other she was brought up with, but when asked who was special to her she replied:

...I had a lot of attention and people talked to me a lot, and, I have uhm, a grandmother, who ah, is deceased now, but I, I would say I had to, if I had to pick one person it would be her...

Lizabeth recalled specifically how important her grandmother was to her because of how warmly other family members talked of her. She felt that she wanted to carry herself with pride like her grandmother had.

There was an understanding that the counsellors had definitely survived and overcome many traumatic experiences as children and youth, but they related these experiences to their overall life learning and were not mired in these past memories. Lizabeth talked about how her experiences were not unusual where she was from and that she saw people who cared in her community. That she knew who she was came from the fact that despite any hard times her



family values were strong. She tells how “I was 10 before I knew I was poor”. Her vision of herself and family life in her own community was not clouded by condemnation because of her experiences, but as she said, her own ability to “detoxify from DIA” helped her to learn to survive and simply demand respect for herself in all her endeavors.

Family history and environment was important to all, but their growth through their learning had an important role throughout the participant’s stories. Indeed, included in their biographical tales was also a focus on each counsellor’s educational history and why where the individuals came from was definitely connected to what they were currently doing in their chosen field. Their learning seemed to play an important role in their current overall happiness with their personal and professional lives.

### Colonialism and Genocide

Prejudice and racism were a vivid part of every counsellor’s personal narrative. But, the individual experiences each had lived through were connected by the workers to greater societal assimilation efforts to eradicate the First Nations in Canada. Four of the six counsellors specifically used the words “genocide” or “colonization” when interviewed. The two other counsellors also discussed oppression on a larger scale in terms of “racism” or “discrimination”. This connection and recognition of the links in personal and political/societal treatment of individuals became an important part of the reasoning for the workers to use their experience and hard-won resilience in order to challenge the larger societal structures.

Every participant discussed how they came across prejudice and what they did when encountering it. Perhaps most degrading and painful were questions the counsellors were asked regarding whether or not they are “real Indians”. Paul related when he moved into a new area:

...my friends in high school used to tell me that I wasn’t a real Indian...they didn’t look like me, and I never knew how to take that, I think they were trying to compliment me, but it hurt.

This kind of distinction regarding race and acceptability by society seemed to present itself again and again in the interviews with the participants.

Lane, Darel, Paul and Carol described First Nations genocide and colonization resulting in alcoholism, racism, poverty, battering, abuse, prison confinement, reserves, residential schools, legal discrimination, blacklisting, and government bureaucracy. Paul talked about the stripping of Aboriginal languages and spiritual practices from First Nations, while Carol, Darel and Laura discussed residential school as being a main oppressive agent of the government. Lizabeth and Laura discussed the First Nations experience of dealing with government officials and how “good intentions are not enough”. In fact, Laura notes that “offers of help did more damage than good” for First Nations in Canada. Lane also made important points noting that she saw First Nations alcoholism and F.A.S. linked to government attempts to encourage the seemingly self-inflicted suicide of First Nations people.

All the workers expressed a clear and direct connection between their individual and community life experience, and the larger societal pressures and systems affecting themselves and their families. Their understanding of their own circumstances was clearly characterized by the acceptance of a larger societal oppression resulting in attempted genocide of the First Nations of Canada. Lizabeth describes this greater societal pressure:

...I don't know, I don't know if there is a really big design out there that actually makes that happen or not but in the beginning that's all you can think of is there's this racist kind of design out there and uhm, the people on this side of the fence are not worthy of exploring options to develop resources for FAS & FAE, you know so in at best what happens is at that, that side of the fence gets blamed.

All of the workers went on to discuss their inner feelings about oppression and genocide.

The importance of knowing yourself through the painful and wonderful personal journey of childhood, while connecting the experience of being Aboriginal to the larger systems affecting

our lives was echoed by all the participants. Each talked about their growth, memories, connections to their families, communities, Nations and experience with racism. But, the most profound part of the storytelling was that each person, in their own way, developed their voice to refute and challenge the negatives they had experienced.

They each now use their voice of knowledge to fight injustice as they described it and add to the strength of their Nations by working in the counselling field. All the counsellors talked about their visions with hope and passion. They describe their journeys as leading to self-discovery and affirmation of their Aboriginal self-identity. This profound sense of resilience was echoed by all the participants with clear acknowledgment of the work yet to be done.

### Being an Aboriginal Counsellor

Most of the participants noted that working with each other as First Nations people has been a powerful and positive experience.

That's really amazing...yeah...I think going back to our traditions, and just instilling the pride is the most important thing...in working with our people, and I think we can overcome a lot of the...the choices we made in our past that, that just reinforces uhm, the strength we have, that's what I feel (Carol).

I believe that's what (pause) that's the reason why I wanted to get into counselling, to help other people and 'cause, 'cause it doesn't really matter to me you know on uhm, where I'm working at you know and it's, if I can be of service to the people you know, then I will (Darel).

All felt that the work they do now is connected to their own identity and their personal life experience. Lizabeth notes that First Nations need to validate each other regarding their potential in the world. And, all the participants discussed how working with their own people was an important part of encouraging positive self-identity and change for all First Nations. As Carol says, "working with my own people" is extremely important to her strong self-identity and

feeling of connection to other First Nations. Each participant continued on to discuss their work experiences, as well as their educational endeavors.

### Doing the Work

All of the counsellors had some kind of post-secondary training, although not necessarily in the counselling field. Most had pursued taking other courses and workshops in counselling and around Fetal Alcohol Syndrome, but only one participant had a degree in the related field of Nursing. Some workers described that becoming a counsellor in this field came by surprise, as three of the participants stumbled into the field through other avenues. The other three workers chose their current profession by design. All of the participants currently enjoyed their work at this time, although most of the counsellors expressed some frustration at the overwhelming nature of the work and needs of the community.

The discussion about education and learning was not limited to talk about University degrees, or education in the counselling field. Learning was discussed moreover as the process through which each individual made their own commitment to understanding who they were and how this knowledge could be focused to help others.

...there's a lot of spiritual elders from that ranch too. And ah, some of them were medicine people and that, so...I remember when I was small they used to...tell me you know, to be patient and to listen and...remember who you are...I give them [clients] exactly what I got from my elders...(Darel).

No, it wasn't a decision in fact for the last seven years, I've been avoiding, ah, taking any kind of counselling...training and I'm doing that now, I'm pursuing my, uhm, certified, certification, 'cause basically I'm good at my job, uhm, and I provide ah, a really good counselling role but never had any training. One of the things about our program, uhm, one of the things I did have was (clears throat) was a really strong belief in family. Uhm, the good, bad and ugly. My family is really important to me and I learned a lot...(Lizabeth).

In essence, the end result of each participant becoming a counsellor was an outcome of years of self-searching, discovery and then formal education.

Lane noted that she had developed her own workshops in order to start working in the field full-time. She felt it was her own initiative, creativity and persistence that prompted others to hire her in this field. Lizabeth had been kicked out of school and got a temporary job in a non-profit agency which then became a permanent position. Paul found himself working at a position in the helping profession because his Aunt had helped him out with a job he needed to pay his bills. Darel, Laura and Carol had all engaged in some form of formal education prior to working in the field. The participants, despite how they came to their jobs, relied on their own knowledge, experience and cultural understanding to meet their work duties and responsibilities.

Upon making the decision to work in the helping profession, the participants found employment in a wide variety of organizations in British Columbia. Jobs ranged from working with the R.C.M.P., social services, adoption services, court systems, health units, non-profit societies, drug and alcohol centers, Native Courtworkers and other First Nations organizations. There was also variety in the job listings within the participant's individual work resumes. Most counsellors had worked in the helping professions for five years or longer, and one worker had worked for over 20 years in the field. All the counsellors expressed much satisfaction and also felt some dissatisfaction with their chosen profession. All of the participants had plans for further work in and/or educational goals connected to the counselling field.

At this time, the participants worked at a variety of agencies in British Columbia, including Native Courtworkers, Crabtree Corner, a genetic disabilities prevention program, Vancouver Aboriginal Child & Family Services Society, United Native Nations, and I-wa-sil (Burnaby Family Life Services). Only one of the positions that the participants worked in was labeled "F.A.S. prevention worker", otherwise all the other workers had worked with families affected by F.A.S. as part of their general job and counselling duties. All of the workers

expressed their need for more information which was First Nations specific regarding F.A.S.

They believed more First Nations workers needed to be hired to work in this area, and that more prevention-focused programs regarding F.A.S. in the Aboriginal and non-Aboriginal communities should be developed.

Each of the participants experienced some frustration or anxiety working in their chosen field. At times, the counsellors felt annoyed by restricted abilities due to funding, time and program service limitations. The workers also experienced personal turmoil and inner pressures as First Nations counsellors.

...if you don't succeed you're going to end up like the other First Nations people, well, they'd say Indians, who are on skid row, so I had, it was like I had two options, make your choice...and, and I chose to try and be more successful...and, and it can hinder my work sometimes today ...(Carol).

...I've worked in, in the uh, social services system, I've worked in the, with the R.C.M.P. and the judicial system and the courts...and throughout them all I've seen what has worked and what hasn't worked, and in my opinion I've seen inequalities in services and in attitudes towards different people...(Laura).

You know, and I think we need to do some really good networking amongst our resources so that it's, there's less infighting about what's going on about who's doing, and all that kind of bullshit, and all these things, the bottom line needs to be services to, you know, our people, and we have workers and, and resources available to give, provide information, but also to bring that sense of belonging...(Paul).

...I went months and months, uhm, just being pissed off (chuckle) because the inequities exist in resourcing ...(Lizabeth).

...and, I think that uh, that is what I sense is going on is, the trap of being at (agency name), part of the trap of ah, workaholism, of, and burnout...of uhm, being overworked in such a way that uh, that's the expectation, becomes the norm...(Lane).

...if we can uhm, educate these politicians in regards to you know, to these uhm, to our people that are affected...then they can provide more funding...(Darel).

The workers discussed how working as a helping agent provided them with many personal and professional challenges. But, belief in self whether or not the counsellor had formal education

was a key factor in each individual remaining in the field. As well, their experiences working in various agencies dealing with F.A.S. also played an important part in their own service delivery styles and influenced their ability to persist in a field they felt was often overlooked, underfunded and dismissed.

### Mainstream F.A.S. Treatment

A variety of long-standing, well-known Vancouver agencies where the counsellors' clients had received services were mentioned by the participants. Mainstream organizations were described by the participants as providing inadequate services for First Nations clients and their families, particularly when it came to providing services to First Nations families affected by F.A.S. The participants described their client's experiences within these service agencies to illustrate the problems they and their clients had encountered. Most of the participants also had a variety of ideas, based on their own and client experiences about how to offer services for First Nations families in a more culturally appropriate and client-friendly fashion.

### Agencies and Service Delivery

Several governmental agencies were mentioned by the participants as providing some assistance to the families they had worked with in the past. The Ministry of Social Services and the Department of Indian Affairs were mentioned by Laura, Darel, and Lizabeth. These governmental agencies were described as having a negative impact on First Nations families and children. Darel notes that he has seen clients who are forced to accept treatment and service that is unjust:

...they're so pressured, you know, by the...by the political movements...whether it be through the Ministry of Social uhm...Social Services...

as well as other hospitals and mental health agencies that Darel named. He continued to discuss how this pressure from large agencies in fact means no one listens to the client, therefore

resulting in the client not receiving the help or services they really need. Laura also noted that Ministry social workers had many misconceptions about First Nations clients:

... when they say culture, it's you know, the social workers, which are non-Native, every single one, (laughs) and there's no workers in the whole area, pretty well, that you know, home workers that go in and help in the homes, other than perhaps, maybe myself and those that are actually living and working on reserve, and when they say culture they think of all of these different uh, ceremonies, the certain dances and all these mysterious things that they know nothing about...

Lizabeth also spoke to the treatment of First Nations families by social workers:

...one of the things about social workers that I first met is that, so many pretend to know everything...want to be perceived as the expert, at all times, they're the expert, and so when I talk to them, I go whatever you need, and I only go in and get ah, what I want and I'm out of there, I'm not here to change non-Native people, I'm here only to help First Nations, because if I want to help non-Native people, that a whole, diff...different energy level, I'm more likely to tell people to fuck off, uh, who are social workers and perceived experts, than anything else...

Later, Lizabeth discussed her clients' experiences with the Department of Indian Affairs:

...I say sometimes all we need, is like a...D.I.A. detox center (clears throat), to detox ourselves from the belief systems that we've inherited because of the Indian Affairs Indian Act...

The workers discussing these systems and organizations felt government agencies play a large role in persistently offering services corrupted by intergenerational racist political policy. It was felt that the effect of this kind of control and denigration further pollutes the individual social worker's perceptions of First Nations, which leads to more misunderstanding, mistrust and oppression.

Other organizations such as Sunny Hill Hospital and Children's Hospital, G.F. Strong, Vancouver Mental Health, mental health clinics, and medical services were also seen as having important roles as agencies involved with families dealing with F.A.S. Unfortunately, four of the participants believed that these agencies had a lack of services available for First Nations families.



...one of the main problems is, you know, is ah, who's going to listen to me? Is what the F.A.S. & F.A.E. clients, you know, are asking...they're so pressured...through the...I guess Sunny Hill Hospitals and ah, GF Strong and ah, Vancouver Mental Health, you know, and then other mental health boards...they're looked on as...if they're guinea pigs (pause)...these different therapists or counsellors are uhm, trying to do different things...medical, the medications side of it, you know, for so many where it's not necessary...(Darel).

...an assessment done in a pro-active way...not, in a, not, you know, with a few other women I know where uhm, and one upcoming where I'm sure it will be that way for her, uhm, where it's more of an opinion to assess this child to see if we should keep the child...(Lane).

...it was a community advisory before Sheway became a program and I started learning more about that, about F.A.S./F.A.E. and I had...it was very confusing because you've got different points of views from doctors that were on the Board, social workers, public health nurses and community workers, so it was quite confusing for me to sort out all the information around it, and I wasn't really sure what it was...(Carol, referring to an F.A.S. Advisory Committee).

...I've seen what has worked and what hasn't worked, and in my opinion I've seen inequalities in services and in attitudes towards different people...(Laura).

Hospitals and other service agencies, though essential in providing care for clients affected by F.A.S. were seen as treating First Nations clients in an unjust way, as "guinea pigs", and providing people with confusing information regarding F.A.S. The counsellors pointed out that the way clients are currently treated by mainstream agencies creates many difficulties for them. For example, Lane and Darel spoke to the way that medical assessments of F.A.S. are conducted and whether the assessment is done for or "to" the client makes a huge difference in the way the client consequently copes with the disease.

A variety of other, smaller agencies, more dedicated to providing services to clients with a family member who has F.A.S., such as SNAP and Crabtree Corner were discussed by the workers. Although there was some feeling that services could be accessed from these organizations, there were still feelings expressed by the participants that the services were not culturally appropriate.

...and one of the problems with (sigh) in those kind of, ah, organizations is that they usually are organized by, ah, white middle class people who are very eager to, to give the best they can to their children and people that I work with that are First Nations, uhm, they will never access, it doesn't matter how good, uhm, how good those organizations are, they'll never access a resource like that because they're all white (chuckle) middle class people (chuckle)...you know. They need their own, that's why we [this organization] exist today, is because somebody who...some of the people out there need their own (Lizabeth).

I've had an Elder coming in before, I don't know if she's not quite an Elder yet, almost, and she, she said she doesn't like coming to [agency name] because she doesn't find it, she said it's so many First Nations women, but it's not, you know... it's not, First Nations friendly... (Lane).

...so, what uh, what happened with that was that I worked there for a couple of years, you know, 75% of the population were Native kids, and uh, there was only myself and another worker, plus my Aunt who were the only native, uh, workers in the, in the agency...(Paul).

The workers discussed how smaller agencies, that they had either worked with or at, had the ability to focus more fully on providing services to First Nations families. Unfortunately, the counsellors and their clients did not consider these agencies to be "First Nations-friendly" in their attitudes and service delivery, and they did not find as many First Nations workers to serve the client population at these agencies, as are realistically needed.

A variety of other systems and service delivery agents impacting these First Nations families affected by F.A.S. were discussed by the participants. The educational system was mentioned by several participants (Carol, Lizabeth and Laura) as presenting some difficulties for the families:

...one of the things was I really recommend is when their children are entering school, that they try to find the best facilities they can to meet the children's needs not for the children to meet the educational system...(Carol).

Lizabeth compared the commitment of workers to First Nations children who have F.A.S. She talked about her sister who is a teacher on reserve in isolated communities and the non-First Nation teachers gaining their first teaching experiences on reserves:

...she has an invested interest in those children to see them grow up as functioning, you know, contributing human beings...and that's the connection she has, that's what astounded her the most, is that the teachers that came, technically have that don't they? Becoming teachers of primary grades, they should have that, but because they have no invested interest in their children, they wouldn't learn how to adapt to a classroom full of F.A.S./F.A.E., and pretty soon they're crying, they're writing letters to people, I need a special teacher, well, of course you're not going to get them...(Lizabeth).

And finally, one of the most damaging outcomes of F.A.S. in the First Nations community and how it is handled by society's systems results in what the participants identify as the adoption of First Nations children outside of their families and communities.

...I have read records of my clients and I have, uhm, heard the stories of our birth mothers and fathers who say that the reason they took the baby away was because there was no medical or special facilities in the community to address, for you know, for that mother to raise that child in a good way. So we didn't have the resources, so they took the baby away...(Lizabeth).

Though this final outcome was extreme, it was also mentioned by several of the counsellors as a sad reality for First Nations families and communities affected by F.A.S. Some of the ways that the counsellors' clients experienced the mainstream agencies and service delivery were related by the participants.

#### Counsellors' Reports of Client Experiences

Perhaps the most sad, but often seen, thread presenting itself in this section is that each participant discussed how their clients and families affected by F.A.S. felt and were treated as if they were "stupid". This experience was mentioned by all the participants.

...of all the people who are going to get dumped all over, you know, if we're gonna talk about a chain, or line of people who are at the bottom, you know, tha...that's it, because educationally, they're challenged everywhere, if they spend their entire lifetime trying to cope and deal with people who are social workers, financial aid workers, and all these kind of people who put them down, not because they're First Nations...because they're perceived to be stupid, and they're called stupid and that's not right (Lizabeth).

Darel noted about a boy with F.A.S. in residential school:

...I used to see him bein' picked on too, you know, when he was small, and that, you know, because of his deformities, and that, and because of this uhm, I guess he looked stupid, he looked dumb...

The counsellors' clients also experienced low self-esteem because of their feelings of shame, anger and guilt because they or their children were affected by Fetal Alcohol Syndrome.

...the rest of society views their worth, because they haven't got, you know, a certain amount of cars, their money or education, or ability maybe even to speak, you know speech delayed, so they're they're not as accepted into society and all of those things compound, the self-esteem goes down, and, and it just, it, by the end of their life, you know they're really...they, they've gone really low...(Laura).

...And, that there's, for some there's going to be a considerable amount of guilt, and shame, and denial (Lane).

I feel that the Fetal Alcohol Syndrome impacts our community a lot, but a lot of our people aren't aware of the impact...they're uhm, they're not, they're ignorant in the sense that they don't have the information and a lot of times, it's been taboo to, to look at the, that child who may have been disformed or disfigured at birth, and so they have a sense of fear around really looking at the issues, and are...and if the parents are the ones that...have the F.A.S./F.A.E. children, they have tremendous guilt around what's happened with their child and they have a sense of loss and grief over...and shame, and it just reinforces the shame that we get from, from being oppressed 500 years ago and it comes down that line...(Carol).

The participants discussed how their clients' experiences of being called and/or perceived as stupid touched the counsellors' own personal feelings of guilt, anger, shame, and grief. For all of these reasons, the counsellors revealed that they and their clients had developed a real reluctance to work with and in mainstream service delivery agencies.

Often, counsellors noted that in their experience, the personal perceptions of service delivery agents often turned into blaming and labeling individuals or families affected by F.A.S., which served only to further encourage client resistance to obtain, or participate in counselling efforts.

...I think that, working with the parent, now this is, this is something I think that ah, our experience has been that, if you have children diagnosed, at Sunny Hill or Children's, often times they don't feel equipped, personally equipped to deal with that system...they

don't understand, and they're intimidated and there's also a sense that they are looked down upon, ah, by the staff in those places...(Paul).

Lizabeth talked about societal blaming regarding F.A.S. diagnosed First Nations children:

... You know, we're the ones that, uhm, drank the alcohol, we should have to live with the consequences...

Darel discusses labeling of individuals with F.A.S:

...when I talk to, you know, to anybody with such deformities as that, you know, it's a, it's a label "deformities"...it is, ah, medical terminology...what I see is another human being...

While Carol noted:

...a lot of times they're labeled uh, learning dis...disabled, but they're not...properly meeting their needs, so they don't learn, a lot of times they're just shuffled through school.

These feelings and experiences are described by the participants as part of the frustrating panoply of obstacles that keeps their clients debilitated.

The cyclical experience of feeling overwhelmed by the everyday experiences of racism, dealing with the racist perceptions in the general public and by mainstream service agencies, trying to parent children affected by F.A.S., and dealing with other issues of oppression, leads many First Nations to continue to medicate themselves through drugs and alcohol. Participants discussed how their clients daily experience of such things as poverty, violence, sexual abuse, battering, isolation, physical and psychic pain, parenting problems, their own residential school issues, and finally, generally simply feeling "so tired of the struggle..." (Lane) to fight for their rights, can lead to exhaustion and further entrenchment in their current lifestyle. Faced with these obstacles, finding appropriate and effective support for themselves and their children can be a difficult and trying journey.

Three of the counsellor's examples of particular client challenges stood out in the interviews. The participants' stories connected the lifestyles of families and children affected by Fetal Alcohol Syndrome to the above discussed environmental and social conditions created in this culture, at this time.

...I went up with her a few times to visit the child and, and uhm, I noticed she's really stayed away from the downtown Eastside. I hardly, I've never see...I haven't seen her in about four months. Uh, she's really moved away...I hope that means it's because she's staying clean, might ..doesn't necessarily mean that...may mean she's really doing badly and doesn't want to feel ashamed downtown (Lane).

...I looked at them, you know, the inmates as, not as inmates, I looked at them as, you know, as people. You know, they're human beings and that (pause) they had a problem...a majority of them, you know...are sex offenders...at Agassiz Mountain I noticed some there are F.A.S. and that, but a majority of the inmates that I worked with are, I believe are, are affected by it. You know, that's the F.A.E...(Darel).

...they've never learned to do a lot of things by themselves, 'cause nobody's had the patience to teach them, I'm like, wow, no wonder you've got, you're disabled, I mean people are making you that way, not because you were born that way...(Lizabeth).

These examples point to the various ways that participants view and have seen their client's experiences. But, connecting the understanding of F.A.S. to the larger social structures, including mainstream service agencies and their service delivery techniques, seemed to play an important and unique role for counsellors in how they helped clients challenge their problems. The participants were also very anxious to discuss how services offered to Aboriginal families affected by F.A.S., might be reformed and informed by First Nations practices and understanding for future counselling endeavors, as well as their belief that important social changes must occur in order to de-colonize and emancipate First Nations from systemic racism.

### Aboriginal F.A.S. Counselling Practice

Counselling practice for families and children affected by F.A.S. was defined by the Aboriginal participants in terms of their own identity and work experiences, the life experiences of their clients, but also by three variables which were perceived as strongly impacting and shaping their own service delivery style and skill. Variables discussed by the participants included gender and F.A.S., spirituality, as well as methods, strategies, advice and practice tools used with clients. These particular pieces of the actual practice performed by the participants were deemed to be very important to their overall success with clients.

#### Gender and F.A.S.

Gender was not a specified focal area of inquiry in this research regarding families and children affected by Fetal Alcohol Syndrome. This particular category showed itself through the participant's interviews to be part of the picture of Fetal Alcohol Syndrome. While all of the participants discussed their counselling experiences with a variety of clients, one of the counsellors discussed family work focused more on helping children (non-gender identified), one of the participants talked about providing service to a variety of First Nations people affected differently by F.A.S., another counsellor discussed men and children he had worked with who were dealing with their own F.A.S. issues, while three of the participants identified their clientele to be mainly women who had children affected by F.A.S., and who were often dealing with their own diagnosed or undiagnosed F.A.S. or F.A.E condition.

Laura described her practice as being one that was "family focused".

...I had a choice, for one of the choices was to work with children that are at risk for developmental delays uh, children zero to six and their parents, a family focused model and it was pretty open, it was open to me to create it and...do that within that much of a mandate in any way that I could, to work with the families to prevent the ac...developmental delays or, you know, keep...to lower the risk, and you know, in poverty situations, or in family situations where there's a history of, you know, maybe genetic uhm, disabilities, or family violence whatever it might be...so, I chose that one...

Laura's theoretical ethic and work mandate helped her to form a counselling framework developed around family involvement, values, beliefs and intergenerational issues. Her work occurred with parent and grandparent involvement in the growth and preservation of family health and well-being. She did not specify gender to be a key factor in her service provision, as she discussed her work by using examples of the children, non-gender specific, that she worked with.

Lizabeth discussed a variety of situations that her clients were coming up against, but again the nature of her work and job description determined who she could provide services to and what services could realistically be given to clients. Lizabeth did not discuss gender as being an issue in her work as:

...the people I work with are adopted, fostered, they're adolescents to ahm, adults, ah, adopted parents are sometimes my clients, birth family members, moms, dads, aunts, uncles, I just talked to somebody's second cousin, you know...

Lizabeth also talked about the client demand for her service:

...we don't advertise our services because we'd be way too busy if we did. And so we, uhm, see the people who are really searching...uhm, they are moved by something in their life, it's usually a crisis, something traumatic has happened in their lives that have pushed them to ask, and ask questions and they may find us...

Working with people affected by F.A.S. themselves, or sometimes with the relative of an individual affected by the syndrome proved very complex, as Lizabeth described to me. The connection of gender to her service provision seemed not to be an issue as her clientele seemed to involve a wide spectrum of individuals.

Darel talked mostly about working with First Nations men, most of whom were not diagnosed with F.A.S., but whom he suspected were affected by the syndrome. He described working at organizations such as A.I.M.S. House and within the prison system with men affected



by F.A.S. or F.A.E., and how their behaviors often ended up with the First Nations men going to jail for such crimes as sexual abuse. Darel even questioned his own behaviors.

...my mother, she drank a lot, she died as a result of alcohol and so I was questioning, I was wondering, you know, like with my temperament and that, you know, I am, I am affected by it?

He went on to say about his nomadic existence as a youth that he wandered:

...just from home to home 'cause nobody really wanted me because I was, I was a maniac, you know, in life and that, you know, I didn't care about anybody or anything...

Darel also related how he had worked with some boys affected by F.A.S., and that building self-esteem and self-identity was vitally important to growth and health, this understanding being based on his own life experience. His work, dealing with men in the prison system whom had not been diagnosed with F.A.S. but whom he suspected of having the disease, clearly informed his own approach to the male children he dealt with who had been diagnosed with F.A.S. This connection of the judicial system to the disease of F.A.S. and First Nations men was noted by Darel as being an important issue.

Three of the participants specifically discussed their experiences of counselling and working with First Nations women and mothers. The participants themselves noted that working almost exclusively with women did inform the ways that the participants offered counselling services to their clients. In fact, for all of the counsellors working with women, agency programs were either structured to only accept women, or the nature of the program (ex. Parenting courses) seemed to determine the gender of the clientele. For participants like Carol, who works with First Nations women, gender was discussed as an important service delivery factor affecting the client's ability to get help and then to receive quality, need-specific services. One of the counsellors who works only with women and children affected by the disease, told me about her reasoning regarding why she sees only mothers and not their partners:

...most of the women I see, uh, they don't bring 'em in, he's at the hotel, or he's at the apartment, or he's out on the street, or he's their pimp...or ah, they...or they're single. So, uh, it'd be nice it'd be really nice to expand it, uhm, again, it really comes down to how much staff time there is, and uh, how much actual counselling time there is, and how much space there is...uh, but it'd be really nice to be able to have the time and space to have couples come in and work with both...and the entire family...and it doesn't happen (Lane).

Paul related about clientele dealing with F.A.S:

...what would be a good profile? Yeah, we usually ah, single moms...you know, ah, low education...uhm, usually had their children quite young, ah, ah, sometimes have kids who have defined, or suspected, ah, alcohol or drug syndrome...there are the families that have...been highly dysfunctional, 'cause they...with the alcohol...and a lot of times ah, you know, there's been sexual abuse in the family...

These three counsellors also described how the women they had encountered in their agencies often try to deal with their children affected by F.A.S., their own addictions and other personal issues, on their own.

Participants discussed a variety of difficulties in helping First Nations women and children to overcome some of the problems they face. As Lane notes:

...if a First Nations woman is going to go into a group and say she's an alcoholic...and that she abuses substances, and in addition to that says, to the point where she drank when she was pregnant, I think the amount of shame just in saying I'm a First Nations woman and being proud of that...is all on it's own it's...and then you've got alcoholism, and then you add that she experienced uhm, pregnancy and substance abuse at the same time...

She later mentions:

...I feel that a First Nations woman comes out and sort of sees herself representing her community. I know that I struggle with that a lot...and, anytime I went anywhere, I thought that people aren't educated that we're all unique, you know, in our nations and in our person hood. Uhm, but if they take everything I say as to represent all First Nations people, which some people have and still do, well that really creates a struggle in order for me to get my needs met.

Carol related her tale about starting a group for F.A.S. affected children and their mothers. She wanted to help provide the mothers with information about F.A.S. and to encourage the women

to support each other with their new knowledge and shared ideas about parenting and coping with their experiences. About her first group, she relates:

...one was pregnant again and couldn't come to the program at that time, uh, she was just ready to have her second baby (swallow) and the other one we lost track of, and she had had uhm, she would, every time she got pregnant she would drink, but when she had the baby she'd sober up, so she could have 2 or 3 years of sobriety between pregnancies, but as soon as she got drunk, she'd drink...as soon as she got pregnant, she'd drink again, which was, I thought, backwards to me, to me it's the other way around, but she, this is how she'd cope with it and it was probably just the issues around uh, around uhm, being pregnant...

Overcoming the burden of shame and guilt regarding F.A.S., lack of personal and community support, intergenerational issues, and moreover, gender oppression, were described by the counsellors as presenting extremely complex and difficult life challenges for Aboriginal women.

The participants' counselling practices for children, men, and women were not so much different in style, but were adapted to reflect the needs of their clientele, with distinct recognition of the reality of the oppression and issues that their clients must face. For half the counsellors, the realities of life for First Nations women and the direct gender oppression that they encounter presented one of the most difficult blocks placed on their clients' path to healing. In terms of providing a comprehensive service, the practitioners also went on to discuss how spiritual practices informed their service delivery.

### Spirituality

Spirituality today for First Nations people is eclectic in practice and varies in form like it does for every other people. Clearly First Nations people are not a homogenous group of individuals and spiritual practices that are passed down through the ages to the Heiltsuk of Bella Bella are very different from those handed down to generations of the Hare of the North West Territories. The ways of knowing who we are as individuals, how we worship, what is sacred and how we observe the sacred, varies greatly from place to place, and people to people. What

it is possible to say about First Nations spiritual practices is that spiritual understandings, creation stories, teachings of the sacred and worship, form a central piece of cultural identity and cultural construction as they do for other cultural groups and races of people.

First Nations people today practice a variety of spiritual and religious ways. Within the First Nations community there is much debate about spiritual practice, how it is performed and what is considered “new age”. In this paper, I would not wish to debate, or declare what is acceptable spiritual practice and what is not. Indeed, I only wish to put forward the notion discussed by Pam Colorado and Don Collins (1987), who write in their paper entitled “Western Scientific Colonialism And The Re-emergence of Native Science”, the spiritual is a key component of a First Nations scientific paradigm, or world view. Therefore, this research reports only the ways in which the participants described the spiritual, or their own practices, and the debate about legitimacy of Spiritual practice, or where Spiritual ways and ceremonies originate, I will leave for other individuals to pursue.

All of the participants spoke about spirituality and how it informed their service delivery and counselling framework. Indeed, the participants had strong opinions about spirituality practiced in their field. Each of the participants defined spiritual practice in their own way. Most believed that spiritual practice plays an important role in the counselling relationship, although not all of the practitioners felt comfortable using this way of working with their clients. Discussion about spiritual practice was often accompanied by much emotion by the participants and was felt to be important personally for each of the practitioners.

Participants discussed how spiritual practice was important for them to acknowledge and share with their clients. Laura discussed how spirituality was important to work with in her practice:

...it's a different feeling, I'm wondering if I can describe it fairly...it, it's a feeling of huh, that everything has feelings, uhm, it's a feeling, I quite often hear about a Creator, rather than a God, it's, and it's not, like when I work in the white community, for instance, which is also part of my job, I don't hear, you know, about God and religious aspects so much, but in the Native community, I'll often hear little phrases, and you know, that mean something to someone other, you know, about the Creator doing this and that, or, or a rock having a life, or something must have meant something, or providence that this should happen, just those types of things...

Laura went on to say:

And, that bonding, bonding between the people and going back to the old ways, too, to have that feeling of solidity, or it does give them a feeling of, of, of roots somewhere to come from and to work, something to work with...you, you know...and there's a sweetness to it, something that hasn't really been lost, or tampered with, or destroyed, it's something that can't be taken away or changed, and it's something that's very unique to that culture...

The feelings and experiences of the sacred and spiritual described by this practitioner are a real part of her practice with her clientele, and her feelings regarding spirituality were shared by some of the other counsellors who also incorporated spirituality into their service delivery and practice.

Paul discussed in a heartfelt way his own feelings and connection to the Creator and a spiritual service delivery practice. He felt that this aspect of professional service was extremely important, but he found it very difficult to work in an agency where it was more difficult to introduce some spiritual practice in a daily way into his work with his clients, as the clientele were not solely First Nations people. In terms of positive changes within the First Nations community, Paul noted "the heart of the change is uh, is our connection to spirituality and our beliefs". But Paul also discussed the challenges he overcame, including being raised as a Catholic, to accept his current spiritual practice.

...the creator is the creator, and uh, there are many steps and many ways to acknowledge that place...and to practice your spiritual beliefs...and, so, I've chosen uh, our native ways now...

Paul described how ideally working within a holistic framework and program meant including spiritual practices, honoring all aspects of the human being, bringing his brothers and sisters back to the circle, and incorporating the ancient ways into his counselling practice.

Darel, Carol and Lane talked about the kinds of spiritual practices and methods they used in their own counselling service. Darel talked about acknowledging the “Indian spirit from within” in his clients and that he has and does introduce clients to sweat lodges, Indian medicines, Pipe carriers and Elders as part of reconnection to a First Nations spiritual way of life. Carol discussed using healing circles, smudge, eagle feathers, sacred objects, honoring ceremonies and Elders to help her clients. Lane also said she used and would like to use more often with her clients talking circles, smudges, what she described as other “traditional things”, as well as involving Elders in healing and counselling. The understandings about sacred objects, spiritual people and ways involved in helping the practitioner’s clients are as varied as the practices themselves. There was no one description by any counsellor regarding how or when these pieces of their practice were used. These pieces were felt to be important to their professional work, but the use of spiritual ways and people was dependent on the client-counsellor relationship and on client need.

Lizabeth believed strongly that the way people use spirituality is strictly a personal choice. She also felt though, that to properly and appropriately honor a spiritual life it is important to become educated about a total spiritual practice. Lizabeth felt eclectic First Nations spiritual practices were sometimes done for “selfish reasons” and noted it was essential that people understand their beliefs in totality. She related to me that for her clients she would give all the information she could about spiritual practices as she understands them, but she would also direct clients to others whom she felt could talk about spirituality, and she made a special

effort to try to get her clients to connect to their family members who might know more about their own people's practices. At one point, Lizabeth smudged with a client and she described her reasoning why:

...I didn't know what to do and I said, what I did was not traditional practice, it was the best that I could think of to do under the circumstances...

She described her respect for other people's ways of practicing spirituality and stated that she felt she had more learning to do regarding this subject. Further discussion with the participants pursued other avenues of counselling practice and ways of working.

#### Methods, Strategies, Advice and Tools

The participants in this study shared their own personal ways of working with First Nations families and children affected by Fetal Alcohol Syndrome. The practitioners' thoughts about the ways in which they approached their clients included discussion about how this made a difference to their success with clientele. Talk about practice issues included: clients needs, community responsibility regarding Fetal Alcohol Syndrome, methods of working with clients, as well as agency structures that stop and/or encourage participants in their journey to health and balance, and finally, the use of practice tools. Throughout all of these thoughts shared by the practitioners, perhaps most important to all discussions was the notion of demystification, not only of the disease, but of the client-practitioner relationship.

All the counsellors felt that their approach to the clientele made a huge impact on their success in providing services to clients. In discussing their own approaches the participants mentioned words like respect, honor and dignity. Participants believed working diligently with understanding of people's cultural and familial history, as well as seeing the clients as human beings and not as "cases" encourages client trust. Practitioners found it necessary to nurture clients and not force the relationship and many found being gentle and slow was effective.

Perhaps, most of all, simply re-affirming clients, their abilities to parent and function well, and offering hope for the family and their future was deemed crucial to positive outcomes.

The practitioners also saw as important not trying to be a “boss” (Darel), but offering services, “...slowly, providing information in a non-threatening way and in a non-judgmental way” (Lane). As well, the practitioners discussed the fact that their communication should be clear. And, two of the counsellors mentioned how important it was to explain to clients exactly the kind of services they offer, as well as to be able to say “I don’t know” (Lizabeth) to clients when they don’t have knowledge of something, and being able to say “No” (Lizabeth) to a client’s, or another practitioner’s, demands.

Also discussed by counsellors was the importance of validating the clients’ knowledge and reassuring the client that they are the expert of their own experience. The idea that the practitioner is an agent in the process of healing and is not the “expert” regarding the child and/or family’s life was also mentioned by the counsellors. As Laura said, “Just allow them to be themselves and to admit and work with their weaknesses...”. All of the practitioners discussed the importance of allowing clients to discuss their specific needs and wants, encouraging their own ability to problem-solve, and validating their ability to take care of themselves and their children. For family members and/or children affected by F.A.S., finding pride in their identity was noted as extremely important by several of the counsellors.

...they are a human being, this is their name and this is their date of birth and this is where, the band where they come from and that, you know, and this is who they are and this is why they should be proud of themselves...(Darel).

Finally, all of the counsellors specifically noted that having First Nations counsellors working with First Nations families and children affected by F.A.S. was pivotal in the healing journey for their clients. This reiteration of including identity as part of healing was mentioned many times



in terms of building client self-awareness, but it was also discussed in terms of using this link through identification with the counsellor, as a role-modeling tool, which the counsellors' felt helped to lead their clients through more successful counselling efforts and encouraged the client to make better life choices.

Issues regarding the communities that clients were living in and society's attitudes towards Fetal Alcohol Syndrome were discussed by the participants. All the participants revisited their own experiences with racism, as has been mentioned, but in terms of helping their clients affected by F.A.S. they felt their own internal understanding of racism was key to their experience in helping clients to face the difficulties of F.A.S. and their lifestyle choices. Practitioners saw that the clients' and their own memories of residential school, racist laws, governmental and religious oppression, as correlated to the First Nations experience with family violence, alcohol and drug use, and family breakdown. As Carol noted:

...I think we, and I'm sure probably I haven't worked with non-Native families, but I'm sure they look at the same issues, but because of the race that we belong to the, the issues around oppression, that's attached to that is one of the biggest factors that we have to look at, and I think that's what makes it more unique for us to work with our people, because uhm, we, we can send our clients to a non-Native uhm, F.A.S./F.A.E. group, but they might not benefit from it and they may, they may get the information for actual uhm, parenting skills, application of the parenting skills, but they may still carry around a lot of the feelings of the loss and grief, the shame...

This strong connection with clients and identifying with the client's experiences was expressed not as a negative factor in the client-practitioner relationship, but was a connection which allowed the relationship a strength that was effective, powerful and unique.

The communities within which clients lived were also seen as being a vital factor in determining whether clients received effective treatment. Bringing people together to help them understand the disease was talked about by all the practitioners, either in terms of public

education and/or making more resources available to families and children. Darel expressed his personal concern regarding community understanding about the disease:

...A.I.D.S. and H.I.V. and that...was, uh, so quiet, but now it's...recognizable by the community and it's O.K...but with F.A.S./F.A.E...it's still...the community still smirks on them when they see it...and so...when that happens to them it...does affect...the families...it just, the communities can't recognize it...like they're blind.

Community support for those affected by Fetal Alcohol Syndrome was defined as a crucial component in controlling and stopping the growth of the disease, but was also seen as a critical part of the effort to help those people already dealing with F.A.S.

A variety of methods and strategies that the practitioners used with clients were detailed in the interviews. Cultural and historical understanding was expressed by the participants as important to good practice with First Nations clients. Educating the clients about alcohol and drug use, Fetal alcohol Syndrome, as well as helping the clients to understand medical assessments from hospitals, their child's development rate and other medical information, helped to demystify the disease. Encouraging the client to learn to network with and use the systems available to them, as well as to effectively advocate for the client was expressed by the practitioners as important. In general, encouraging the client's own independence, self-sufficiency and resilience is what all the practitioners found as essential in helping children and families to thrive despite an F.A.S. diagnosis.

The practitioners also shared more specific ideas regarding direct practice. Laura noted that understanding such cultural practices as oral history allows the practitioner to use this within their own counselling sessions in order to help the client further their understanding of F.A.S. in a way that is culturally appropriate and effective. Other examples of practice methods and strategies include using pictorial language models and including sensory integration into counselling sessions, in other words, listen and speak instead of giving written information to

clients. Many of the practitioners mentioned that important for the client-practitioner relationship was attention to client spiritual practices; knowledge for practitioners and clients regarding the client's own cultural history; and making places safe for people to share emotions.

Practitioners also felt it important to be teaching life skills to clients and to help clients to develop safe boundaries for themselves with others, including attention to developing routines, limits, and learning about societal rules and social cues. Most participants felt it important to offer individual and group counselling for clients and to have two facilitators available for group sessions. They felt it was important to keep certain sessions open only to Metis and First Nations families and have peer support groups available. Finally, being able to learn together with the client about their needs and how they can realize their potential was expressed as important to the healing process.

Though all of the practitioners discussed their own practice methods, strategies and advice, Lane and Paul also discussed their thoughts on how an agency should and should not offer services to clients affected by Fetal Alcohol Syndrome. All of the participants mentioned needing more First Nations workers working with First Nations families affected by Fetal Alcohol Syndrome, but Lane also mentioned the importance of having a single agency-based multi-disciplinary team working with clients, as referring families and children to many different agencies for services poses many difficulties for clientele. She notes that an ideal agency would provide very effective services wherein "pro-active" work could be done with clients in a "homey atmosphere". Both Paul and Lane note that integrating F.A.S. understanding, assessment and counselling into general practice within agencies would help to design a very effective counselling program for clients. Lane discussed how she would like to see more space built for Aboriginal women to meet in and support each other regarding the issues of alcoholism

and F.A.S., where daycare is available on-site and First Nations activities are encouraged for families. Other important pieces of practice include the tools that these practitioners use in their service delivery.

The use of some “home-made” client tools were reinforced by the counsellors. For example, clients used the television as an instrument to teach children about facial expressions relaying inner-emotions. As well, cultural and spiritual objects were used by some practitioners with their clients. Laura discussed being creative with the tools that one uses:

...I will use animals to teach the social boundaries, and uh, we'll go out, say to my farm, stand with the horses, and say, well this is why the horse is moving back, his ears turn to the side, do you know what he's saying to me? He's saying that I hear you over there making a noise, or I see you creeping up to me and you're only going to get within 3 feet, and then I'm gonna move back because I feel threatened, and then, you say well, you know, people sort of do that too...

Practitioners also mentioned using genograms, medical assessments, manuals on F.A.S, books/videos such as The Broken Chord (Dorris, 1989), filming oneself or others to understand facial expressions, magazines, sharing information on practical parenting skills and using manuals on parenting, as well as using art and play therapy with clients and their children, and attending F.A.S. conferences with families.

### Emotions and Feelings

Each worker's tale of how they found their heritage and identity, and how they integrated their understandings into their practice was emotional and full of feeling. The connection to being and identifying as an Aboriginal person was passionately expressed by all the workers through their stories. Feelings of deep sadness and happiness, pain, suffering and tolerance were talked about. Each worker's face changed with their thoughts, expressions sometimes growing slowly from deep thought and contemplation, but sometimes rushing up from wells of memory. The feelings discussed by each worker and the emotion expressed is important to connect to each

practitioners' counsel and practice. This theme is meant to help connect the pieces of the other themes, all the individual experiences and insights to each person participating in this research...for storytelling is made real when it is connected to the unique presence of the individual.

Carol expressed much pride and happiness about her accomplishments. She was especially pleased with her daughter's first footsteps in the helping field:

...and I guess what I'm really happy about is, uhm, my daughter, I have two grandsons, and my daughter didn't use alcohol or drugs through those pregnancies, uh, one is almost 5 and the other one is uhm, 2, almost 2, but uhm, that she was able to go through this training with me, I was really proud of that, so I think it's a generational thing that's happening...

She also expressed her deep connection to feelings expressed by her clients about their loss, grief and shame because of , in her words, "colonization". Carol also happily discussed how her own strengths allow her now to work with her people.

Darel was quiet and reflective. He took his time answering the questions, but was clear that his peace came from an introduction to God through the Christian religion and his own reconnection with the "old ways" as he has learned them since childhood. He felt very connected to the people he worked with and was emotionally touched by his clients who are affected by F.A.S.

...The impact, you know, it has on the community I work in here, you know, at present...it's really sad.

Darel expressed sincerity and ardor regarding his work with his community and his own connection to his identity as a First Nations man.

Lizabeth was very honest about her experiences. She was thoughtful and strongly opinionated regarding the questions asked. Lizabeth was also very clear about what First Nations people do in the helping professions.

...we've learned how to do two, three jobs and we've learned how to make do with our ten dollars and make it look like fifty, and I said we...and, we have acquired a lot of really good skills, and what we need to do is validate those skills, while we need to do is maybe pat each other on the back for surviving and doing all those things and then when people do a shitty job, be able to be free to say that too...

She was angry at the injustice First Nations have endured, but very readily described how she uses this powerful energy to challenge and change the systems she works with.

Laura expressed herself clearly and frankly. She discussed her search for identity with a softness and a sadness.

...I had a real driving need then to go back and find out what had gone wrong and see if there was anything I could do, by then there's a lot of resistance, my face was very white and I feel uhm, you know, very Native inside, and, and, a lot of my values and beliefs coincide, you know, with First Nations roots, but I looked very white...

She remembered confusion and isolation as a Metis child, but also smiled at thoughts of hunting and fishing at home with her father. She obviously enjoyed her work in her community and felt great compassion for her people.

Paul was expressive and soft-spoken. He talked very passionately about his spirituality and his identity as a First Nations man.

...the challenges are great for us to be, to identify for ourselves who we are, you know, and what is our heritage. My belief is that, I believe in our healing ways and I believe in...and I believe that we have, have to help the world.

He described much pain throughout his life, but believed that the pain was set in his way to give him understanding. His dedication to the Aboriginal community was obvious and very loving.

Lane became very upset at the thoughts of her childhood and the extreme experiences she had lived through. She told me sadly:

...I resented being a First Nations female, because it was, I didn't know really what it meant.

Her memories of the confusion regarding her identity were very painful, and struggling to find solidness in herself had clearly been a difficult and profound journey. However, her overwhelming strength, brightness and hope shone through the tears she shed in our interview session.

This is what I saw expressed by the participants in the interviews I conducted. This is not meant to be a total recollection, but shadows of the range of emotion and feeling expressed by the six workers regarding their own identities which connects them so strongly to their work and clients. Emotion and feelings are not simple to describe, and I can only honor the participant's honesty and sharing by making their experience real to the reader through adding this brief synopsis of the human energy behind the discourse with each individual.

### Summary

The meaning of these words written about and by the participants in this paper will only come to be meaningful by the action they inspire. To try and capture the individual's experience with a disease that influences their community so profoundly is a difficult task. Never have I wanted so much to make certain of my ways of working and sharing information. To respect the individual participant's words and knowledge is what I hope I have captured in this chapter.

As Lee Maracle (1990) wrote in "ORATORY, Coming to Theory":

Our orators know that words governing human direction are sacred, prayerful presentations of the human experience, its direction, and the need for transformation in the human condition which arises from time to time. (p. 5)

This chapter is full of story spoken by people about their personal experience. These stories were shared with the belief that the words and thoughts would change our ways. The fact is that even within the storytelling itself, there lies a transformation and change in the worker's experience and in my own understanding. Now, the information is passed on through this thesis to the

community. Finding voice is the purpose of this research. That the participants were able to discuss their identity, their passions and professional experiences, reveals in itself a profound statement regarding First Nations strength and resistance to historical oppression.



## CHAPTER FIVE

### CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to endeavor to understand the experiences of Aboriginal practitioners who offer services to First Nations families and children affected by Fetal Alcohol Syndrome. Currently, the research in this area is practically non-existent and the voices of First Nations counsellors do not often appear in academic research. This research project will help to expand the knowledge base of all who access this information, by providing the reader with information regarding Aboriginal identity, being an Aboriginal counsellor, mainstream F.A.S. treatment, and Aboriginal F.A.S. counselling practice. This thesis offers a great number of implications for counselling practice and further research possibilities.

#### Implications for Practice

This study indicates that Aboriginal identity was very important to acknowledge not only in the lives of the clients, but of the practitioners. It was very clear that events in the personal histories of the practitioners gave them the impetus to pursue their work. The practitioners discussed how their self-discovery and understanding of their past was very important for their eventual pride in their culture and recovery from their own experience of racism. This knowledge then led the practitioners to connect their personal history to the greater systemic forces that have brought First Nations through such a brutal history of colonialism and attempted genocide. The important implication in this piece of the research is that knowing one's self can lead to greater empowerment in the counselling profession.

For all of the participants, becoming a First Nations counsellor partly came out of the experience of being oppressed. And furthermore, the end result and value of struggle in providing counselling services was the pride that the participants felt when empowering their

own people to become healthy. My perception was that their work was taken on because of the personal sense of care for and about other Aboriginal people, and not because they wished to "fix" the problems or people they worked with. The significance of the contribution to the counselling and social work field from First Nations counsellors is their perception that this work is not only honourable, but a responsibility, a duty for the greater good and for the children in the seventh generation to come.

Mainstream treatment practice was discussed by the workers with a sadness because of the paucity and ineffectiveness of programs offered to Aboriginal families faced with F.A.S. Clearly, counselling practice and programs/agencies working with First Nations families should be developed with an understanding of First Nations history in Canada. Without the acknowledgment of the history of Aboriginal Nations, important and vital understandings regarding a client's current familial and living situation are not envisioned as pieces of the client's whole environment. This kind of practice does not serve the purpose of helping clients, but further degrades and pathologizes behaviour, attitudes and abilities due to counsellor ignorance and prejudice.

Mainstream treatment organizations need to develop and work from emancipatory theoretical frameworks within which they can evaluate how to determine client need and offer service to First Nations clients. Mainstream services, as they were discussed by the First Nations counsellors in this thesis, are not satisfactory for the clients with whom they work. Counsellors discussed how mainstream services tended not to have a "human face". With a more knowledgeable approach, First Nations input in program planning, services directed to Aboriginal families and more Aboriginal counsellors available, mainstream agencies and programs can begin to provide more effective services for all Aboriginal people.

The counsellors also noted that in mainstream service very often First Nations and F.A.S. clients are not given sufficient information to take on tasks themselves. Therefore offering specific information to the client and demystifying “counselling” is an important part of the process of working with First Nations families affected by F.A.S. Overcoming systemic and socio-cultural barriers means counsellors and other professionals in the social services field should be taking part in specific cultural training programs to understand First Nations history, which may also serve to help deconstruct internalized oppression and racist feelings. Practitioners must undertake their own self-care, therapy and healing in order to offer service to clients that is not inadvertently, or blatantly affected by personal biases and discrimination.

The participants in this research noted other barriers delaying or stopping First Nations from receiving proper counselling support and other medical/mental health services. These barriers include:

- lack of daycare services,
- lack of basic material needs for families (food, shelter, etc.),
- poverty,
- lack of social support/community support,
- lack of education regarding F.A.S.,
- lack of First Nations “friendly” support groups and parenting programs,
- costs of counselling services,
- obvious/subtle discrimination practiced in agencies,
- lack of First Nations counsellors,
- mystification of F.A.S. and the counselling process,
- lack of any personal connection to client experience,
- lack of safety within a counselling environment.

Further research into these areas and how they influence Aboriginal families and children affected by Fetal Alcohol Syndrome is recommended.

Finally, the practitioners all discussed their experience that First Nations counselling services may include spiritual practices. However, this should be defined by the client and/or Aboriginal counsellor, and it was felt it should be honoured as a legitimate part of the

counselling process. Tools used by Aboriginal counsellors, perhaps not used by others in mainstream organizations, might be used within counselling practice, if it is practical, done in a way that honours the practice and the Nation from whence it comes. Counsellors felt that community services should include treatment of families affected by F.A.S. as part of general agency programming, not leaving these families to be served only by medical service agencies. The practitioners also felt that community support and services to all new mothers needed to be improved, as well as to children with Fetal Alcohol Syndrome and their families.

The counsellors voiced that their work would be more effective if women with alcohol and drug problems could receive flexible services that are non-threatening and that include an understanding regarding cultural needs. They felt that their methods, strategies and advice could help deliver culturally appropriate services to clients, and their expertise should be consulted in program planning, service delivery and policy formation. The counsellors expressed their views that mental health services for First Nations, and in particular, women with mental health problems, need to be made a priority, available and easily accessible for all who need the services irregardless of their government-identified status.

Several of the practitioners noted that moral and financial support for healing centers in communities, as well as trained First Nations counsellors are needed across the country. The validation and legitimization of client experience by the First Nations counsellors' own life experiences, provides the connection of cultural understanding which lends itself to an environment of safety for the client. The importance of a counselling practice including a knowledge that F.A.S. is a symptom of larger systemic issues cannot be overstated. Some tools and ways of working discussed within this thesis which lend themselves to emancipation from oppression include bringing our Elders into our practices; bringing extended family into the

familial support system; and using holistic practices which involve acknowledging our human emotion, mental health, our physical body and spirit as part of the total self involved in healing.

Clearly, good practice was defined in terms of de-colonization. This process necessarily means re-direction of current counselling practice and policy. First Nations identification of our own emotion and feeling, our connection to self pride, worth and identity are all life lessons vitally important to the process of enabling us to provide services to our people. Through realization of our own history and strength, we empower ourselves to rediscover the voices of the First Nations, our health and our future.

On a greater global level, it is also essential that First Nations leaders, those involved in First Nations counselling, social work, health and child welfare services, also be involved in practice that acknowledges and honours the cultural experience of First Nations in Canada. Those First Nations counsellors and professionals working in the field, with their particular and valuable insights into the problem and the solution of this disease, need to be able to contribute to national politics and opinion. We need to be involved in the production of curriculum, history, policy, law, research and other aspects of socio-political discourse affecting our lives.

Understanding the connection of colonialism and attempted genocide, to racism and oppression as it is practiced on First Nations today is extremely important to being able to effectively counsel Aboriginal people and especially those families affected by F.A.S. In my field, social work, I have found that acknowledgment of oppression in my own attitude and behavior with clients can have a significant positive effect in the client's willingness to work with a "professional". The counsellors discussed how not forcing particular services on a family, but respectfully working with the client to develop a plan within their ability and need is an

honourable approach to counselling. Treating clients with respect and focusing on strength and capabilities will help the client to realize their own potential and strength.

Judgments and pre-conceptions of First Nations have been made without any understanding of the historical discrimination through which Aboriginal people have struggled. First Nations have come to medicate themselves and then pay for their guilt and anguish through loss of their children to drugs, alcohol, residential schools and foster care. These experiences have profoundly affected Aboriginal people, and therefore the places where they can begin to feel safe to recover and thrive are limited.

The difference in practice which includes an environment of safety for a client was discussed by the First Nations practitioners as coming down to the genuineness of community support, counsellor practice and self-pride. As well, the honesty with which a counsellor and/or agency uncovers its own connection to First Nations discrimination may encourage a huge change in policy and practice which further emancipates clients and workers to build a relationship in honesty and with trust in the reality of our lives. But, the change of the individual must be connected to the greater social change encouraged through challenging current systems and structures on a global scale.

Public policy must be established at governmental, institutional and community levels in order for this disease to be planned for and truly understood. The planning of public policy regarding F.A.S. should take place with the help of individuals diagnosed with F.A.S., their caretakers, families, social workers, therapists, as well as with the input of institutions and government. Developing effective policy is an often difficult and exasperating job, but public policy has the potential to change lives dramatically. F.A.S. will no doubt be a prominent future concern in federal health and welfare planning.

### Suggestions for Further Research

As there is so little research in the areas of First Nations counselling practice and First Nations families affected by F.A.S., there are many possibilities for further research in this field. Research may include exploration of the experience of First Nations counsellors and counselling practices. Academic exploration may also be focused in the area of Fetal Alcohol Syndrome education, prevention and intervention. In this section, I suggest areas of research regarding a myriad of subjects, for academic studies regarding Aboriginal counsellors' voices and experiences, the subjects of First Nations counselling and Fetal Alcohol Syndrome are scarce.

Representation of First Nations people is very important to include in the academic realm, as the expression of any experience means that it exists in the world of academia, as it does in the hearts and minds of the subject of any thesis. Therefore, the academic community can partake in learning about experience, knowledge and cultural identity not necessarily considered their own. The meaning in this particular kind of exchange of information in today's world is not always limited to the academy, but may be used to change policy, practice, politics, and in the end, our individual perceptions of cultural experience. The importance of research is that it can transform experience and this is my reason for partaking in and directing research. Participatory action research projects with communities could help to begin the process of establishing a dialectical relationship between community members and academics focused on reciprocity and social change.

Areas of exploration for mainstream agencies might include a focused examination of client-centered services. First Nations counsellors, practice, processes and ideas should be further explored in order to understand ways of working that are perhaps not yet acknowledged by academic institutions and "legitimate" counselling programs. Along the same lines, research

needs to be conducted with the families receiving services by non-Aboriginal and Aboriginal agencies in order for professionals to understand what successful service delivery looks like to the client. Finally, the experience of those First Nations clients who had received any counselling services regarding F.A.S. and those who had received no counselling services might be represented in the academic research, so as to understand if any counselling is, in fact, better than none.

Mainstream services offered through medical programs are becoming more specific as the disease is understood, but the counselling service to children and families after diagnosis is sadly lacking. Medical institutions and counselling agencies need to inquire through academic investigation what is important to offer families after diagnosis. Professionals need to question such things as how parents and children with F.A.S. cope with their life situation, what services are available for and/or are needed by families with children affected by F.A.S, or by adults and parents who are coping with their own F.A.S.? Much of the conventional academic investigation has focused on the medical issues surrounding F.A.S., but what of the dialogue regarding the client's needs and how their needs can be met by our current and future service agencies?

As was explored in the research, the experience of the First Nations counsellor is important to take into account when offering counselling services to families affected by F.A.S. Counsellors need to question and understand their own identity and life traumas. Inquiry might be focused on such things as whether boys or girls are treated differently once diagnosed with F.A.S., does spirituality acknowledged in the counselling practice help to make successful outcomes, and what kinds of practice tools are helpful within the counselling process. Providing



service with recognition of culture is also an important area of research not yet well explored within the academic realm.

As well, more research of a qualitative nature needs to be conducted to enable the academic community to understand and acknowledge the First Nations voice silenced by racism and oppression. This work is extremely important as it reflects the unacknowledged and powerful understandings of First Nations people. It also begins to uncover and challenge the tapestry of racist oppression woven over academic institutions, as well as challenging conventional counselling techniques with cultural and spiritual alternatives/additions to service provision.

Finally, on a more global scale, further research should be conducted on Fetal Alcohol Syndrome in Canada and in First Nations communities, representing both rural and urban locales. In particular, a research focus on how fast this disease is spreading in our cities and how we are providing intervention services is vital to altering the growth of the disease. It is important to know that research regarding effectiveness of our current prevention programs and intervention services for families affected by this disease were not easy to find in the literature.

Through this study, I have found that generic treatment programs are not helping First Nations who are trying to deal with F.A.S. The First Nations counsellors expressed their understanding of why mainstream programs do not work and how they have developed their own techniques, style and practice to accommodate their community. Perhaps the most important ongoing focus of research is to find within any treatment program focused on F.A.S., what successful intervention look like. Important for professionals and the public are data bases and resource centers on F.A.S. where we can more easily access information regarding the disease.

Possibly the Internet poses a new way to exchange and build our academic knowledge and conduct collaborative research.

I am not sure if enough can be written about the experience of Aboriginal peoples in Canada, about the history of power dynamics, cultural appropriation and colonization running through our family anecdotes and the historical journeys of our Nations. But, for those First Nations people who also now deal with mental illnesses and/or disabilities, and who are trying to parent children who may be affected by Fetal Alcohol Syndrome, there is an incredible lifelong struggle to maintain health in Canadian society. This experience of First Nations history, cycles of oppression, and ongoing discrimination connected to our current living situations are not well understood inside or outside of the academic institutions. These areas need to be the focus of truthful and respectful research endeavours.

Oppression occurs within ourselves as it does outside in the world, but without representation of our voice in every place in society we are unacknowledged and forgotten. First Nations will not and can not wait for society to understand our position. Instead we find the ways, push the boundaries, and write the words to further empower ourselves and our communities. As a social worker, I have begun this research only to realize that it is a process that is still inspiring change in me and those who read this thesis because of the thoughtful words shared by the participants. The practitioners engaged in this study have inspired me and shown me that whatever future studies are conducted on F.A.S. and First Nations counsellors, research is still only as important and relevant as the action it inspires in our real lives.

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**APPENDIX 1**  
**AGENCY INTRODUCTION LETTER**

School of Social Work  
2080 West Mall  
Vancouver, B.C. Canada V6T 1Z2  
Tel: (604) 822-2255

Dear Agency Director:

**RESEARCH PROJECT: First Nations professionals' interventions and service provision  
for Fetal Alcohol Syndrome affected First Nations families.**

My name is Renee Robert and I am a social work student at the University of British Columbia. I am currently engaging in research to explore the experiences and perceptions of First Nations human service professionals who provide intervention and services to urban First Nations families affected by Fetal Alcohol Syndrome.

I believe the best way to understand First Nations human service professionals' practices is to explore this experience by gathering information from First Nations Syndrome affected families, an increasingly profound problem in the First Nations community. I think this will make a significant contribution to the knowledge base of other practitioners in the social services field.

I am requesting permission to interview First Nations human service professionals at your agency. The interview format will be informal, similar to that of a discussion, and will require approximately two hours to complete. The focus of the interview will not deviate from the experiences and perceptions of practitioners who provide services to First Nations families affected by Fetal Alcohol Syndrome. Confidentiality and anonymity will be strictly observed for the participants, your agency, and clients mentioned.

The focus of this project is not to evaluate your program, or to gather any information relating to service delivery, treatment models, or any other aspects of your agency functioning. Your agency has the right to decline to participate, or withdraw, from the research at any time. And, I will be happy to elaborate on any aspect of the research project at any time.

If you are in agreement with this proposal, I am asking that you sign and return the enclosed agency consent form, keeping a copy for your records. I am hoping to complete interviewing by March 15, 1994, and would appreciate hearing from you soon. Please distribute the enclosed introductory letter to any staff member who has provided intervention and service to First Nations families affected by Fetal Alcohol Syndrome. The staff members can contact me directly if they are willing to participate in this research project. I will then arrange a mutually convenient time for the interview.

.../2

## APPENDIX 5

### INTERVIEW GUIDE

RESEARCH PROJECT: Guides within the Circle;  
First Nation counsellors experiences with First Nations families  
affected by Fetal Alcohol Syndrome.

RESEARCHER: Renee Louise Robert, B.S.W.

FACULTY ADVISOR: Dr. Kathryn McCannell, Office phone: 822-6622

INTRODUCTION: Thank you for your participation. I am very interested in your opinions on this subject and appreciate this time with you.

The purpose of this research is to explore the experiences of First Nations counsellors who provide services to First Nations families affected by Fetal Alcohol Syndrome.

This is not a test of your knowledge or skills, no answer is right or wrong. I am only looking for opinions based on your perceptions. This interview is informal and relaxed. Please ask questions at any time.

Question 1:

How did you become a counsellor working with First Nations families affected by Fetal Alcohol Syndrome?

(Probes: Personal experiences; formal education; traditions; Elders.)

Question 2:

In what ways do you think Fetal Alcohol Syndrome impacts the community you work with?

(Probes: medicine wheel - physically/mentally/spiritually/emotionally; short-term; long-term; personal insights.)

Question 3:

If I were a First Nations counsellor beginning my practice with First Nations families affected by Fetal Alcohol Syndrome, what do you feel would be important for me to know about providing service to these families?

(Probes: History; Native Nations; family composition; health practices; traditions; medical services; Formal education; First Nations medicine; support techniques; counselling strategies; material needs.)

Question 4:

What do you find to be the most effective treatment strategy for First Nations families affected by Fetal Alcohol Syndrome?

(Probes: Counselling techniques; medical model; the medicine wheel; prevention; health/sickness; holistic healing; spirituality; tradition; political/economic change.)

## APPENDIX 7

### SHORT FORM SURVEY

INFORMATION ABOUT YOU FOR THIS STUDY -  
PLEASE CHECK THE FOLLOWING ANSWER THAT APPLIES TO YOU:

1. Gender: \_\_\_\_\_ Male \_\_\_\_\_ Female
2. Are you status, non-status, or Metis?  
       \_\_\_\_\_ Status \_\_\_\_\_ Non-status  
       \_\_\_\_\_ Metis
3. Marital Status  
       \_\_\_\_\_ Married \_\_\_\_\_ Single  
       \_\_\_\_\_ Divorced \_\_\_\_\_ Living with Partner  
       \_\_\_\_\_ Separated \_\_\_\_\_ Widowed
4. Do you have children?  
       \_\_\_\_\_ Yes \_\_\_\_\_ No
5. Where do you currently live?  
       \_\_\_\_\_ Vancouver \_\_\_\_\_ North Vancouver  
       \_\_\_\_\_ Richmond \_\_\_\_\_ Burnaby  
       \_\_\_\_\_ Surrey \_\_\_\_\_ Other

Please answer the following questions:

6. Your age: \_\_\_\_\_
7. How many years have you worked as a human service professional? \_\_\_\_\_
8. How long have you worked in the First Nations community? \_\_\_\_\_
9. Your academic credentials: \_\_\_\_\_
10. Other professional credentials: \_\_\_\_\_
11. (a) Are you involved in any traditional First Nations practices and traditions?  
       No \_\_\_\_\_  
       Yes \_\_\_\_\_  
       (b) What practices and/or traditions are you involved in?  
       \_\_\_\_\_  
       \_\_\_\_\_  
       \_\_\_\_\_

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You are under no obligation to answer any questions.