A STUDY OF THE NEEDS OF ALTERNATIVE CAREGIVERS

WHO PROVIDE CARE

FOR

ADOLESCENTS AND YOUNG ADULTS

AFFECTED BY PRENATAL EXPOSURE TO ALCOHOL

BY

HOLLY GAMMON

A thesis presented to the University of Manitoba
in partial fulfillment of the requirements for
the degree of Master of Social Work

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ABSTRACT

Fetal alcohol syndrome and fetal alcohol effects have become a great concern over the past two decades here in Manitoba. Many of the children affected by this disability are being taken from their biological homes and placed in foster and adoptive care. Women continue to be the main care providers for these children through their childhood and on into their adolescent and adult years.

This thesis is a qualitative analysis of the role of women as care providers to persons affected by prenatal exposure to alcohol. Sixteen women were interviewed in an attempt to understand their experiences of raising and caring from fetal alcohol effected adolescents and young adults. The thesis explores the caregivers struggle to understand the disability, learn new parenting strategies and gain support from service providers. A phenomenological approach was taken to analyze the interviews.

The women were found to be struggling with the huge task of caring for this population group and with the lack of services available to provide ongoing support for FAS/FAE individuals as they reach adulthood. It is apparent that society has not found a way to support this population group. These women continue to nurture and sacrifice their personal development, career prospects, and mental and physical health to care for this population group well into adult years. Society continues to exploit these women.

We as a society need to find ways to better support persons who take on the task of caring for individuals with FAS/FAE. Community based approaches to looking after persons affected by FAS\FAE are preferred over those that continue to exploit women.

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CHAPTER ONE

Introduction

Reason for Study

In the past twenty years our society has come face to face with the issue of Fetal Alcohol Syndrome. We now know that the consumption of alcohol during pregnancy can lead to some very damaging and irreversible consequences for the unborn baby. Genetic and behavioural research has given us a much clearer understanding of how a child can be physically, cognitively and/or neurologically effected by alcohol during pregnancy. Parents. schools, the justice system, the mental health system, and others in relationship with alcohol-effected persons are faced with gaps in understanding how to assist this population group, and gaps in the services available to promote the affected child's well being.

This qualitative study takes a look at some adolescents and young adults affected by prenatal exposure through the eyes of their female caregivers. It focuses on the journey that the caregivers travel as they seek to provide the best care they can for these individuals.

My interest in this area comes from the daily struggles I have had over the past ten years as a social worker trying to understand and plan for the needs of children in care or at high risk of coming into care. Many of these children have come from homes that are troubled by alcohol/drug abuse and they are children affected by prenatal exposure to alcohol. I have often sat with the birth, foster or adoptive parents and listened to their struggles and their pleas for assistance in managing their children's troublesome behaviour and in accessing appropriate services. Many caregivers had to relinquish care of a particular child and the caregivers end up feeling like they have failed. As a result many of these children end up with a history of unstable, disrupted placements. Streissguth et al. (1991), in their study on 61 adolescents and adults prenatally exposed to alcohol found:

> They had lived, on average, in five different principal homes in their lifetimes (not counting receiving homes or temporary shelters). Only 9% were still with both biological parents: only 3% were still with the biological mothers. Of those for whom accurate data could be obtained. 69% of the biological mothers were known to be dead. Although many died of alcohol-related illnesses, others died of other alcohol-related causes such as suicide, homicide, falls, and automobile accidents. Nearly one third of these patients with FAS/ARND/ARBD were never raised by their biological mothers; they were given up for adoption at birth or abandoned in the hospital. (p.1965).

In my experience, many foster and adoptive parents are not provided with knowledge and/or training to deal with the complexities of caring for these children prior to placement. Placement disruption is understandably common. There is a need for increased matching, preparing and supporting of families for the long-term care of children effected by prenatal exposure to alcohol to reduce this placement disruption. Placement disruption is detrimental to children in general, however, children affected by fetal alcohol have an even greater need for stability and structure as a result of the very nature of their disability. Research by Streissguth et al. (1996) indicates clearly the consequences of disrupted placements in what is termed "secondary disabilities" (pp. 30-63). Their study will be considered more fully in the "Theoretical Framework" chapter below.

Many adolescents affected by fetal alcohol are not ready to live independently at the age of eighteen. In Manitoba, children leave the care of Child and Family Services at eighteen and if assistance is required, one of the adult services should become involved. This has been another frustrating part of my work experience. There have been numerous times when these adolescents were not eligible for any adult services. Community Living applications are turned down because eligibility is limited to those with an IQ of below 70. Vulnerable Persons assistance is likewise unavailable because eligibility depends upon a diagnosis of a mental health disorder. Often nothing can be found that fits these person's needs and they get no assistance with the complexities of living in our fast paced society as a person effected by FAS/FAE.

At the same time, I see many teenagers involved with the child welfare system with either suspected or diagnosed FAS/FAE spiralling out of control during their teenage years. They run from placements, abuse substances, drop out of school and become involved with the legal system at an alarming rate. It is often hard to know what to offer them, or how to help them.

With this background I began to wonder how we as a community in Winnipeg and the surrounding area could be more responsive to the needs of persons with FAS/FAE. I began to wonder how the caregivers themselves are coping and what answers they might be able to offer with respect to the children they are raising and struggling to prepare for adult years.

Caregivers in this study are limited to foster and adoptive parents. In particular I wanted to speak to female caregivers who traditionally have been the primary care provider in the home. The rationale behind this decision is that a vast majority of children with FAS/FAE live in alternative care (Streissguth and Kanter eds. 1997, p. 102-103; Streissguth, Barr, Kogan and Bookstein, 1996, p. 18; Streissguth et al., 1991, p. 1965; Streissguth and Kanter, eds. 1997, p. 23). As children get older and reach adolescence, they generally have more difficulties living up to societal expectations and norms. The brain damage that causes gaps in comprehension, generalisation, and ability to determine cause and effect, becomes more and more obvious and problematic (Streissguth, 1997, p.136, Groves, 1993, p.49 and Doris, 1997, p. xxv). As a result, it is reasonable to assume that fewer and fewer children affected by alcohol can be maintained in their biological families, especially when alcohol use by parents is an ongoing issue.

A second reason why I have chosen to limit this study to foster and adoptive parents is that it is very difficult to gain the trust of birth parents. They are often reluctant to share their experiences. This is understandable since their stories are often riddled with issues such as guilt, addictions, sexual/physical abuse, poverty, etc. This study cannot begin to address these underlying and oftimes interrelated issues.

Research Questions and Methodology

This research is influenced by my personal worldview. I adhere strongly to a feminist perspective. My experience is that the majority of the primary caregivers for those affected by prenatal exposure to alcohol are women. It is therefore the women's voices that I have sought out and listened to when trying to discover the caregiver's realities and needs. Within this framework, which I will explain in more depth later, there are two significant groups of questions.

The first group of questions assists in getting a much clearer understanding of the challenges women substitute caregivers in Manitoba are experiencing as they care for fetal alcohol effected individuals. The following are some of the questions I tried to answer in this study:

a. What are the tasks and responsibilities that are specific to the care of this particular population?
b. What do these responsibilities look like to the caregivers and what do they "cost" in regards to personal time; career prospects; family time?
c. How do these women feel about the care they provide?
d. Do they feel valued by society?
e. What are the burdens?
f. What are the joys?
g. Why do they foster?
h. Why do they adopt?

The second set of questions focuses on the support, knowledge and the services that these women have been able to access:

a. Do the caregivers feel that society has a place for these young people?
b. Do the women feel supported by family, social workers, service providers, etc.?

c. Are the present services adequate? If not, what is needed, what can be changed, and how do we get there?
d. Do they have the knowledge and skills they need to care for these individuals?
e. Where did they get this knowledge and skill?
f. Is more training needed, and if so, where should this come from?
g. Are women being exploited by a lack of services and a task that is not shared enough by the wider community?

What I am proposing is that these caregivers be given a voice to share their struggles and joys with the hope of expanding our understanding and ability to support their valuable efforts. My hope is that this research will add to the existing research on the needs of this population group. A quantitative research study was circulated by the Province of Manitoba (The Children and Youth Secretariat) and the Coalition on Alcohol and Pregnancy in January of 1998 which was meant to obtain some answers respecting what services are needed for all ages of the population effected by prenatal exposure to alcohol. I had hoped to gain access to the specific findings relating to older adolescents and young adults from that study to supplement the research in this project. I was able to obtain a summary of the research and used it as a comparison/supplement to my research findings. At the same time, it is my hope that the research undertaken in this thesis will enhance the research done by the Province and the Coalition on Alcohol and Pregnancy. As a result, in the bigger picture, I hope this study will assist stakeholders and care-providers in this province to focus more specifically on providing a courageous response; one that supports those caring for persons effected by prenatal exposure to alcohol.

Relationship of Research to the Human Service Field

This research has a number of implications within the human service field. It impacts on social workers in a wide variety of ways. I personally work in the area of child welfare. I work every day with families and children who are struggling with alcohol and drug addictions. Decisions are continually made about who will care for children that have been affected by prenatal exposure to alcohol. The decisions that are made about young children have a major impact on how these children will or will not "succeed" as adults in years to come.

Social workers, however, are not the only ones grappling with these issues. Every sector of society within the human service field feels the impact. The education system struggles to find ways to help these individuals learn basic knowledge essential to participate meaningfully in society. Behavioural specialists struggle to learn methods of helping these individuals learn the skills necessary to provide safety and appropriate boundaries. Speech pathologists work hard at helping these children with expressive and receptive language delays. The legal system struggles with assessing responsibility and developing creative sentences that will protect society and lower recidivism.

Aboriginal people in Manitoba are also grappling with the issue of FAS/E. A disproportionate number of Aboriginal young children are affected by FAS/FAE and a disproportionate number of these young children continue to be taken from their families to live in foster or adoptive families. Over sixty percent of the children in care with Winnipeg Child and Family Services are Aboriginal (Winnipeg Child and Family Services Strategic Planning Workshop Information Package, 1998, p.18). It is a time when Aboriginal people are trying to heal themselves and their communities and to restore their cultural identity. However, the continuing results of colonisation, residential schooling, and ongoing discrimination are very evident. They are manifested in the poverty and alcohol addictions that hamper attempts to keep their families intact, build a sense of pride, and experience success.

Some good initiatives have been introduced and implemented both for the prevention of FAS/E and for pre-school children with FAS/E here in Manitoba. These programs include STOP FAS, Aboriginal Head Start, the Interagency FAS/FAE Program and many others. The programs are helpful and necessary. However, the need to continue learning and the need for a co-ordinated societal response does not end after childhood. When individuals affected by fetal alcohol exposure reach adolescence and young adulthood they do not miraculously fit into our society.

> At no point is advocacy on behalf of the child more necessary than at adolescence. Improper programming combined with the expectation that a chronological adolescent should be able to manage on his own is a prescription for disaster. Alcohol-effected adolescents need an individualised program that addresses their social behaviours and life skills in context, no matter what their IQ level. The higher the level of functioning of the child, I have found, the greater the need for specific programming. The alternative is frustration, failure, and social isolation culminating in a cycle of alcohol and drug abuse (Lutke, 1993, p. 87).

In my work experience I have encountered many women who have been looking after children affected by fetal alcohol for a long period of time. They are usually strong advocates and have expertise in understanding what their children need to find success and happiness in adult life. However, they have run into many brick walls while trying to access services and their knowledge of these children and their children's needs is often not taken seriously. Ignorance about FAS/E and inflexibility in standards of eligibility for services are the most common obstacles.

Some of the primary issues to be addressed in adolescence are the development of independent living skills, social relationships, and employment. Many of these individuals cannot live independently. Streissguth and Kanter, in their book, The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities write that in one study of 90 individuals over the age of 21 with FAS/FAE, eighty percent were living dependently (1997, p. 34). The question for all of us is how we provide supports to help persons affected by FAS/E become as independent, or appropriately dependant, as possible.

The same study indicates that eighty percent could not gain employment (Streissguth, p. 34). We must ask ourselves some difficult questions. How can we reorganize or change the environment to make meaningful employment possible for these individuals? What shift in values and expectations do we as a society need to make in order to assist them to become contributing members?

If we do not respond to these questions, there is a significant cost financially and emotionally to them, to those who love them and care for them, and to society as a whole. What better resource do we have to answer these questions than the "experts" who have watched them grow, who have fought to have their children understood and to see them given a fair education and chance to live a fulfilling life?

Limitations of the Research

The research in this study was limited to sixteen participants. These participants came from Winnipeg and the surrounding area. Although this number of participants is well suited to the research in a qualitative study, it is not large enough to make generalisations to the larger population. However, there were some clearly dramatic differences in the availability of certain resources outside this area.

The study also only reflects a specific group of caregivers. This group includes substitute caregivers, that is, adoptive and foster parents. Biological parents likely share some of the same struggles and issues but this study does not reflect that group.

This study involved interviews with female caregivers. While the vast majority of caregivers are women there is a group of male caregivers. They may well share many of the same joys and struggles. The present study does not pretend to reflect their experience.

Another limitation of the study is that it does not attempt to address the underlying issue of addictions. The author of this research study wants to state clearly that her personal bias does not lie in the realm of blaming birth parents for the birth of children with fetal alcohol. In her opinion this is a much too simplistic answer. Our society holds a substantial responsibility for the addiction struggles that plague many of our poor, marginalized, citizens. Education can help but will not ever completely alleviate this disease. We must develop strategies to treat people in a more respectful, fair and just manner. Factors such as residential schooling of Aboriginal children, childhood trauma, poverty, racism, discrimination and inequality are at the root of many of the addictions that plague our society today. This paper will not delve into solutions and answers for healing these societal ills. The author, however, acknowledges that unless the root causes of hopelessness and powerlessness are dealt with in a concrete and planned fashion we will continue to force individuals into the despair and emptiness that perpetuates addictions and results in children being born with alcohol related disabilities.

> We know from the aetiology of FAS/E that its roots lie to a large extent in poverty and the economic and social marginalization that poverty produces. ... The best form of prevention lies, therefore, in fashioning policies that will eliminate the structural factors that create and maintain poverty. Recent progress on this front is, however, discouraging. In the last decade and a half, we have lost ground in our efforts to curtail poverty in Canadian society. Poverty is on the rise and, as it effects more people its outcomes – such as poor physical and emotional health, inadequate nutrition, low-standard housing, higher infant mortality rates, substance abuse and FAS/E will continue to increase (Ternowetsky, 1999, p. 88).

CHAPTER TWO

Theoretical Framework

Fetal Alcohol Syndrome and Effects

Introduction

> Fetal alcohol syndrome is not just a childhood disorder; there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviours present the greatest challenge to management. (Streissguth et al., 1991, p. 1961)

Consumption of alcohol during the pregnancy can lead to some very damaging and irreversible consequences. It needs to be noted from the outset, that each child is an individual and not all are affected in the same manner during the pregnancy.

> Depending on the dose, timing, and conditions of exposure, as well as on the individual characteristics of the mother and fetus, prenatal alcohol exposure can cause a range of disabling conditions (Streissguth, 1997, p. 56).

After birth the same continuum is at play. No two children have the same disposition, personality, life experience or level of care. Therefore, no one is able to accurately predict the outcome for any particular child.

Alcohol is a Teratogen. "Teratogens are substances or conditions that disrupt typical development in offspring as a result of gestational exposure and cause birth defects" (Streissguth, 1997, p. 56). The science of Teratology makes it possible to establish a number of relationships between alcohol consumption and possible level of damage done to the unborn foetus. The first is the relationship between the amount of damage caused and the dosage of alcohol consumed. Secondly is the relationship between the amount of damage caused and the timing of the consumption during the pregnancy. The final relationship is between the patterning of the consumption and the amount of damage caused.

Without delving into the specifics of the science of Teratology, a number of conclusions can be drawn. These are:

a. more damage is done the greater the consumption of alcohol;
b. consumption during different trimesters effects the specific developments of the foetus at that stage; and,
c. patterns like heavy bingeing expose the foetus to high levels and extended periods of exposure causing increased damage (Steissguth, 1997, pp. 56-65).

FAS (fetal alcohol syndrome) is a medical diagnosis used to describe a pattern of birth abnormalities found in children exposed to alcohol (and/or drugs) before birth. Research indicates that anywhere from 6% to 40% of very heavy drinking women give birth to children with FAS (May, 1995, p. 1550). The incidence of FAS is .5% to 3% of the population and ARBD/ARND (alcohol related birth defects or alcohol related neurodevelopmental disorders) is 2 to 6 times greater (May, 1995, p.1550). Other research indicates that fetal alcohol syndrome is recognized as the leading known cause of mental retardation in the United States (Abel and Sokol, 1986, p. 51; Mattson & Riley, 1996; Burgess & Streissguth, 1992). It should be noted, however, that those affected have a wide range of intellectual ability (Giunta & Streissguth, 1988; Barr, Bookstein, Kogan & Streissguth, 1996). Intellectual functioning is only one of many areas that can be affected by prenatal exposure to alcohol.

Information circulated at the 2000 Manitoba: Prairie Northern Conference on Fetal Alcohol Syndrome (May, 2000) indicated that

> The world-wide incidence of Fetal Alcohol Syndrome has been estimated to be two cases per 1000 births. In Manitoba, estimates range as high as forty cases per 1000 births. Incidence may be as high as 20% of all births among some high risk groups." (p. 25)

In 1995-1996 a study on a First Nations Reserve in Manitoba revealed that 10% out of a sample of 178 children "were identified to have physical, cognitive, and behavioural problems attributable to prenatal alcohol exposure". (Chudley and Moffatt, 1996, as cited in 2000 Manitoba: Prairie Northern Conference on Fetal Alcohol Syndrome Syllabus) (pp. 158-159).

History

Although the term "Fetal Alcohol Syndrome" was not officially recognized until the early 1970's, many references can be found throughout history reflecting awareness that drinking alcohol may be harmful during pregnancy. Streissguth (1997) has provided a helpful synopsis of many such references. The bible in Judges 13:7 admonishes: "Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks." In 1726, a report to the British Parliament by the College of Physicians says, "Parental drinking is a cause of weak, feeble, and distempered children" (Report by the College of Physicians to the British Parliament, 1726). In England, during the late 1800's and early 1900's numerous studies were done trying to distinguish children born to alcoholic mothers and fathers, but there was widespread disagreement as to whether alcohol caused any damage. In 1942, Haggard and Jellinek (alcoholism experts) ascribed the "Greater incidence of feeblemindedness, mental disorder, idiocy, and epilepsy found among offspring of alcoholics during the first half of the 20th century to the "poor stock" and social upheaval in alcoholic families" (Streissguth, 1997, p. 36).

Studies were also being carried out in France. Here, there was not as much controversy. In 1957, Rouquette, published a thesis in which she concluded that maternal alcoholism posed very grave dangers for the developing foetus and child. By 1968 Dr. Paul Lemoine had done research and cited a similar pattern of physical anomalies, growth deficiencies and behavioural difficulties (as cited in Streissguth, 1997, pp. 38-40).

In 1973 Smith and Jones coined the term "fetal alcohol syndrome". Children with similar characteristics had been independently identified in France (Lemoine et al., 1968) and in Seattle (Jones et al. 1973) as a specific subgroup of children born to alcoholic mothers (as cited in Streissguth, 1994, p. 74).

Definitions

To be diagnosed with full FAS (Fetal Alcohol Syndrome) children must have abnormalities in each of three categories. A diagnosis of FAS will also be given if these three categories are all evident even if the maternal alcohol exposure cannot be confirmed.

The first category is growth deficiency for height and weight, below the tenth percentile. The growth retardation usually begins with low birth weight, there is a low weight to height ratio, and/or weight may decelerate over time. Individuals with FAS typically are quite short and often have a thin, emaciated look because they have fewer fat cells. During puberty, some girls gain weight, making them look a little chubby, but boys tend to stay slender well into adolescence (Fox, undated, p. 2)

The second set of criteria is a characteristic pattern of facial features and other physical abnormalities. Evidence of facial abnormalities include microcephaly (small head circumference), microphthalmia (smallness of the eyes), eye abnormalities (e.g. wide set eyes, ptosis, short palpebral fissures), flattened nose bridge, underdeveloped cheek area, a long indistinct philtrum, thin upper lip, small lower jaw and strabismus. These features are more distinctive when the children are young (Stratton, 1996, pp. 72-73; Fox, undated, p.2).

The third category is dysfunction of the central nervous system. This area of dysfunction often creates the most difficulty in our present systems and is the focus of the struggle to change systems to meet the needs of persons effected by prenatal exposure to alcohol. The dysfunction manifests both as cognitive difference and behavioural challenges. Many of these disabilities may not be apparent at birth or even be noticeable until school entry. Some of these differences and challenges include developmental delay, hyperactivity, poor impulse control, learning disabilities, poor gross motor co-ordination, decreased attention span and lower average IQ (Stratton et al., 1996, p. 73).

A child who exhibits some, but not all of the physical signs of FAS and also shows learning and behavioural issues that imply central nervous system damage is diagnosed as FAE (Fetal Alcohol Effects). The Institute of Medicine, in May of 1996, suggested changing the designation for FAE to ARBD and ARND in order to be more accurate. ARBD or Alcohol Related Birth Defects is the diagnosis given to a child who exhibits physical anomalies such as small stature, large joints and/or gross and fine motor control issues. ARND or Alcohol Related Neurodevelopmental Disorders is the diagnosis given to a child who shows evidence of central nervous system damage that includes behavioural and cognitive (learning) issues (Streissguth, 1997, pp. 29 - 30). [1]

Children who are FAS often appear handicapped. Children who have ARBD or ARND often appear perfectly normal. This latter group are now believed to be at greater risk for what Anne Streissguth refers to as "secondary disabilities" (Streissguth, 1996, p. 30). These are disabilities that individuals are not born with but develop over the years (i.e. mental health problems, confinement, disrupted school experience, etc.). These secondary disabilities are often the result of:

a. a failure to understand the needs of these children;
b. society having no place for them to feel productive;
c. the school system not being able to meet their learning needs.

Secondary disabilities place a person at a much higher risk for maladaptive behaviour. The difficulty arises most often when an ARBD or an ARND child's appearance does not conform to the diagnostic criteria of FAS. If a diagnosis is not made, the usual interpretation for their behaviour is that they are choosing to misbehave or not comply and they are treated accordingly.

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[1] The women interviewed are familiar with the terms FAS/FAE so I will be using the term FAE to cover

In spite of this apparent difficulty there is still debate about the value of labelling. On the one hand labelling is harmful to children, because, once individuals are labelled people treat them as inferior or in other stereotypical ways. On the other hand, labelling is necessary because it is the only way that these individuals can be identified and gain both understanding from the public for their behaviour and services to assist them with the learning and adaptive difficulties that face them in the 'real world' (Caldwell, 1993, pp. 119 - 122).

Aase (1994) suggests that physicians are not adequately doing their part when they fail to ask pregnant women about alcohol consumption, especially middle and upper class women. There also appears to be a reluctance to diagnose FAS/FAE if a child is white and/or middle or upper class. Diagnoses are made much more readily, however, if the child is from a minority group or from a lower socio-economic position. This may be the result of misguided kindness, fear of offending or prejudice, but the end result is that children with fetal alcohol disabilities are not understood and have a lifetime struggle trying to fit into mainstream society.

Society in general believes that the majority of children affected by fetal alcohol are Aboriginal. However, fetal alcohol issues are noted across cultures and countries. The belief that FAS/FAE is a Native issue appears to be largely based on the fact that many studies have been done with American and Canadian Indian reserve populations (Jones, undated, p.7).

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both ARND and ARBD

Cognitive and Behavioural Outcomes of Alcohol Exposure

"The behavioural outcomes of alcohol exposure are of greatest long-term significance for the effected individuals and for society which must provide educational, medical, and social services" (Coles, 1992, p.13). The behavioural and cognitive deficits that will be discussed in this section appear daunting. However, it must be kept in mind that every child is affected differently and all attributes are not seen in every child.

> Maternal alcohol abuse has an enormous range of effects on children. While many are mentally retarded, others have IQs in the normal range. While some have such serious learning disabilities that they need special classes, others can manage in a regular classroom. Ironically, as we become more and more aware of the subtle effect of prenatal alcohol exposure, we will identify more and more children who are only mildly affected (Kleinfeld, 1993, p.5).

It is also important to remember that there are some remarkable individuals in our society that have FAS/FAE. Some children show remarkable talent like the story of Cindy who received her associate of fine arts degree (Anne Gere, 1993, pp. 55-68). Her parents, knowing that Cindy found school challenging, looked for alternatives where Cindy could feel successful. Hard work and artistic ability led to a degree in 1992. Other individuals show outstanding ability in a variety of areas including music, sports, and storytelling or constructing.

This does not discount the many common characteristics that make it difficult to live with and care for children affected by fetal alcohol syndrome and effects. These will be noted and expanded upon in the next section.

Many individuals with FAS/FAE are limited because their intellectual functioning is impaired. FAS/FAE is commonly "recognized as the leading cause of mental retardation in the United States" (Streissguth et al., 1991, p. 1961). Other individuals with FAS fall within the normal range of intelligence and some have exceptionally high IQ's. For example, in research done by Streissguth (1991) the "range of IQ scores was wide, from 20 (severely retarded) to 105 (normal)" (p. 1964). The average score for this group of 61 was 68, a score that is at the upper end of the mentally retarded range. The categories used ignore the fact that for these persons there is a "marked discrepancy between their IQ levels and their level of Adaptive Behaviour" (Streissguth, 1996, p. 66). That is to say, there are other disabilities such as poor social skills, poor impulse control, inability to generalise, no understanding of consequences, learning disabilities, and poor life skills that render them unable to function independently in the community.

Attention deficit disorder, with or without hyperactivity is very common in children with FAS/FAE. Streissguth's study in 1996 showed a 61% frequency of ADD difficulties in her sample of 415 individuals (pp. 34-35). Children with ADD or ADHD have a short attention span, are easily distracted, and have difficulties organizing and completing assignments. Changes to the central nervous system may alter the flow of signals and responses between the brain and body. Children with ADHD are often intrusive and can be both destructive and aggressive. On the other hand, children whose attention deficits are not accompanied by hyperactivity can go unnoticed and unassisted in classrooms for years.

Medication is one possible response but is not always the best answer. There are other techniques for assisting these children within the classroom but most are time intensive. These techniques have the advantage of dealing with ADD or ADHD behaviours at the same time as other, often unrelated, learning difficulties that medication does not address. Available techniques include such things as keeping the classroom smaller, structuring activities closely, limiting the visual stimuli, patience, careful transitioning, organisation and having a teacher's aid to do some one-on-one work with the child (Lindsay and Preston, 1999, p.68; Tanner-Halverson, 1993, p. 210 and Tanner-Halverson, 1997, p. 79).

Learning disabilities are also common. Often people have a learning disability in one or two areas. Unfortunately, individuals with FAS/FAE seem to lack processing abilities in many or all areas. They struggle with recording, interpreting, storing, retrieving, and using information. Their abilities are often very unpredictable; they function well one day and poorly the next (Morse, 1993, p. 32). Arithmetic is the most problematic area and as a result many children never learn to tell time or make change. They often have memory difficulties, although their long-term visual memory may be good. They may forget what they just read before they reach the end of a paragraph. They may need instructions one at a time because they are not able to remember the next step. They often have difficulty finding the right words, although they may be very social and verbal. They may know things one week that seem to disappear from their memory the next (Morse, 1993, p. 32).

Many individuals affected by prenatal exposure to alcohol experience speech and language delays. Although children with FAS/FAE are usually delayed in developing speech they become quite "chatty" once the skill has been learned. They may impress casual acquaintances with their vocabulary and apparent curiosity. Unfortunately, the verbal expression camouflages a lack of depth and difficulty recalling stories or events in any detail. The questions asked by children with FAS tend to be repetitious and centre on recurring themes. They can mimic conversations, but do not understand the meaning behind what they are saying (USD School of Medicine, undated, p. 16 and Berg, Kinsey, Lutke, and Wheway, 1995, p. 8).

Kodituwakku, et al. (1992) reported that children with FAS experienced unusual difficulty with problem solving, generalising information and controlling their behaviour. Difficulty learning from experience and planning for the future was also noted. They may not be able to control impulses or drives. Often they cannot comprehend that they have done something troubling and they may show weak predictive abilities and poor judgement. They grasp pieces of the big picture, but the pieces may not necessarily connect in a logical manner or conclusion (Lutke, 1997, p. 181). Other behavioural problems may include temper tantrums and aggression. Children with FAS/FAE are often described as easily irritated and "exploding" at little things. Burgess and Streissguth (1992) describe challenging behaviour as a form of communication for these children. Although it might be natural to personalise irritability or angry outbursts, these behaviours may be primarily expressive rather than simply destructive (p. 26-27).

Some children are very sensitive to outward stimuli. For example elastics, labels, hair bands, barrettes or stiff shoes can be very irritating. Other stimuli like bright lights, or loud noises can also cause problems and/or real pain to some individuals (Hinde, 1993, pp. 136-138).

Lying and stealing are often noted in children with FAS/FAE. Lying may not be a matter of trying to get out of trouble but a misunderstanding of the expectations or a confabulation based on understanding only a portion of the actual circumstances. There may not be an understanding of the interplay between truth and consequences. Stealing, especially for children with developmental delays, has less to do with morality and more to do with the reality that that person is operating from a much earlier developmental place. These behaviours might be a cry for a flexible and responsive external structure to rescue the person from their inability to provide self-containment and self-regulation at the level expected by others (Rathbun, 1993, p. 311-312 and Burgess, 1992, p.25).

The above behaviours are often very frustrating to teachers and parents alike because when misunderstood these children are seen as simply wilful. As students age, their impulsivity becomes restlessness and there is a tendency to “split” when situations become too frustrating. Parents and teachers note such problems as stealing, lying, and inappropriate social interaction. The greatest problem is often a marked discrepancy between seemingly high verbal skills and the inability to communicate effectively. The combination of poor self-control and inadequate communication skills creates learning and social problems that may leave teachers, parents and students feeling frustrated and helpless. Those with FAS/FAE have said "It's like I have holes in my head", or "There's a wall in my head". (Malbin, 1993, p.266-267). Brain scans show structural changes to the brain which bear an uncanny resemblance to these verbal descriptions (Streissguth, 1997, 98-99).

Adolescents and Young Adults

For two decades researchers have looked in some depth at how and what alcohol does to the foetus, how to work with babies and pre-schoolers by assisting them to change the pre-school environment, or to cope within that environment. Only in the last few years have we begun to turn our attention to the adolescents and young adults who are struggling with FAS/FAE. From recent research, it appears that neither these individuals themselves nor their caregivers are faring very well.

The first adolescents studied by Jones, Smith, Ulleland and Streissguth in 1973 were found to have a number of recognisable features. These features included short palpebral fissures, a flat mid-face, a hypo plastic philtrum, and a thin upper lip. These features were combined with continued growth deficiencies and microcephaly. The study showed that physical growth continued to be below average. The adolescents studied were two standard deviations below the mean for height, 1.76 standard deviations below for head circumference and 1.11 standard deviations below for weight (Streissguth and Randels, 1988 p. 142). Other features that became more apparent over time were otitis media, hearing problems, vision problems and scoliosis (curvature of the spine). The nose and chin often lengthened with adolescence, misaligned and malformed teeth were often present and sometimes there was the emergence of secondary teeth (Streissguth and Randels, 1988, p. 138).

The most foreboding and distressing results of the study were found in the persistence and severity of their mental handicap. This study was the first recognition of the long term and debilitating consequences of maternal alcoholism on the offspring – consequences that endured far beyond the lives of the mothers (Streissguth and Randels, 1988, pp. 137-138). Other alarming results of the study found that although individuals with FAE generally had an IQ score about 15 points higher than FAS individuals, children with FAE were having as much difficulty if not more in school and adapting to the social world around them (Streissguth and Randels, 1988, p. 146).

In 1991 Streissguth, Aase, Clarren, Randels, LaDue and Smith did a further study of adolescents and adults with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Similar physical differences were revealed, but the research particularly focused on their academic and adaptive functioning. The individuals tested in this study had an average chronological age of 17. They had "an average level of adaptive functioning of around 7 years"; they "performed best on daily living skills (mean at the 9 year level) and most poorly on socialisation skills (mean at approximately the 6-year level)." The average academic functioning was at a second to fourth grade level (Streissguth et al., 1991, pp. 1964-1965). The inventory on maladaptive behaviours "indicated that 62% of the patients had a 'significant' level of maladaptive behaviours and 38% had an 'intermediate' level" (Streissguth et al., 1991,p. 1965).

> The most frequent types of maladaptive behaviours noted were poor concentration and attention, dependency, stubbornness or sullenness, social withdrawal, teasing or bullying, crying or laughing too easily, impulsivity, and periods of high anxiety. In addition, many of the patients were noted to lie, cheat, or steal, to show a lack of consideration and to exhibit excessive unhappiness (Streissguth et al., 1991, p. 1965).

During adolescence the disabilities that children with fetal alcohol present during their childhood years appear to intensify. Physically, the child is maturing but cognitive and social skills are usually very far behind. The desire for independence in combination with normal hormonal drives appears to intensify the impulsiveness, lack of inhibition and lack of critical thinking and judgement skills. There appears to be an inability to appreciate how one's actions could affect another person. Inappropriate sexual behaviour can become criminal behaviour as the desire to explore sexuality is initiated with no concept of boundaries. Often younger, more developmentally equal children are targeted. There is also a real and substantial risk of children with FAS/FAE being victimised because adolescents have trouble establishing and maintaining lasting reciprocal relationships and are easily manipulated by peers in their search for acceptance (Streissguth, 1997, pp. 136-137; Hornby, 1993, p. 291).

Adolescents with FAS/FAE are often able to talk very well, convincing the general public that they are competent, responsible individuals. Unfortunately, they are often not able to follow through with their plans without major supervision and assistance. As they encounter failure in holding a job, living independently, managing their own money or parenting children, they increasingly end up on the streets or in jail. Withdrawal and isolation are common as is unpredictable behaviour, depression and a higher level of mental illness (Dublenski, 1996, p.13). If they do continue living in families or with friends their caregivers often end up "burnt out".

> I thought that once we got him through school, some of the hard work would ease up. Boy, was I wrong! The challenges of having an "adult" child with FAS are even bigger than school struggles. At least the school environment provided a little buffer zone of security. We have had a year of our son being battered by a world that cannot or will not try to accept him. He doesn't want pity and there is no mercy, not in the job market or any place else. The world expects him to act like an adult and his brain doesn't know how. It is heart rending to watch him try to function socially and suffer rejection and misunderstanding (Groves, 1993, p. 49).

Secondary Disabilities

Research unfortunately reveals that a majority of adolescents and young adults with FAS/FAE are suffering from what is termed secondary disabilities. Secondary disabilities include such things as disrupted school placement, teen pregnancy, use of drugs and alcohol, mental health problems and trouble with the law. Secondary disabilities are characteristics that a person is not born with, and that could presumably be reduced through better understanding and appropriate interventions (Streissguth et al., 1996, p. 67).

It is this suggestion, that appropriate interventions could ameliorate some of the secondary disabilities that has inspired the research in this thesis. Secondary disabilities often arise when the societal systems needed to meet the needs of this population are not in place. This may happen when the health system fails to diagnose individuals or when the education system has failed to find innovative ways to teach students with FAS/FAE. It may happen when caregivers are unable to provide stable homes because lack of skills, training or respite, or when there is no place in the job market able to cope with the supervision needed to employ adults with fetal alcohol disabilities. Secondary disabilities are related to low self-esteem, the despair and the anger of being misunderstood and marginalized. These secondary disabilities are at a great cost to the individuals themselves, their families and society at large.

Streissguth et al. considered six main secondary disabilities. 473 clients were studied ranging from ages 3 to 51. 178 were diagnosed as being FAS and 295 were diagnosed as being FAE. The following were included in their findings:

a. Mental Health Problems were the most prevalent secondary disability with 90% having such difficulties. Mental Health problems include attention deficit problems, depression, suicide threats, panic attacks, auditory and visual hallucinations, and suicide attempts.

b. Disrupted school experience was noted in 60% of the clients. These individuals had been suspended or expelled from school or had dropped out of school.

c. Trouble with the law had been experienced by 60% of the clients. Trouble with the law is defined as having been charged, convicted of a crime or having been in trouble with authorities.

d. Confinement was experienced by about 50% of the clients. Confinement included inpatient treatment for mental health problems or alcohol/drug use, or having been incarcerated for a crime.

e. Inappropriate sexual behaviour was noted for about 50% of clients.

f. Alcohol/drug problems were indicated for about 30% of clients.

In addition to these six secondary disabilities, two additional areas were evaluated to determine how adult clients were managing with self-sufficiency. Of 90 clients over the age of 21, 80% were still living dependently and 80% were having problems with employment. Only seven of the ninety adults in their sample were living independently and without employment problems (Streissguth et al., 1996, pp. 30-63).

The secondary disability study went on to look at factors in the child's environment that might possibly lead to a vast reduction in the development of secondary disabilities. These factors were called "protective factors" (Streissguth, 1996, p.24). Some of the protective factors suggested by their research were:

a. The leading protective factor was living in a stable and nurturing home for the majority of ones life;
b. Not having experienced violence against oneself;
c. staying in each living situation for an average of more than 2.8 years;
d. experiencing a good quality home from age 8 to 12 years;
e. having basic needs met for at least 13% of life.

These very basic needs appear so obvious and essential but unfortunately they are often not available to these children (Streissguth, 1996, p. 64).

Three other protective factors were found to be very important. These were: (1) being diagnosed before the age of six years; (2) having a diagnosis of FAS (rather than FAE); and, (3) having applied for and been found eligible for DDD (Division of Developmental Disabilities) services (Streissguth et al., 1996, pp. 24-30).

From the above research we know that some of the fundamental needs of those affected by prenatal exposure to alcohol are stability, structure, violence free environments, early diagnosis and either assisted work placements or disability allowance. The research in this study looks more closely at the caregivers in an attempt to understand the circumstances they find themselves in as they struggle to parent individuals with FAS/FAE. Caregivers will be given an opportunity to both address issues related to caring for individuals with FAS/E and to express ideas about what additional supports they need in order to provide good care.

The Ethic of Caring: Caring For Those With FAS/FAE

Introduction

Individuals with FAS/E find living in society difficult. Parenting and raising children with FAS/E to adulthood and beyond takes patience, creativity and a great deal of commitment. Children with FAS/E have high supervision needs, their frustration level is low, their activity level is high, and their indiscriminate behaviour is often frightening. These behaviours and many others make them vulnerable to physical, sexual and emotional abuse. Long-term follow up shows that a large number of children effected by prenatal exposure to alcohol end up being raised outside of the biological family. Streissguth et al. studied 61 adolescents and adults. "Only 3% were still with their biological mothers" (1991, p. 1965). Extended family care, foster care, institutional care and adoptive care are the most common care settings (Streissguth, Barr, Kogan and Bookstein, 1996). No matter who is caring for them, it is a major challenge. As a result these children often come into care of child welfare agencies and bouncing from foster home to foster home, or undergoing adoption disruptions. One would expect to find that it takes more than just a single nuclear family unit to provide good care to these individuals. Authors in the social work field have pointed out the need for community involvement in parenting for all children.

> The truth is that child rearing is a collective endeavour in which fathers, extended families, and the whole society play a role, either by taking an active part in the well-being of children or by refusing to do so. The early years of a human life are the most important and formative. They should be the concern and responsibility of more than one isolated, devalued, unsupported person (Swigart, 1991, p. 12).

Unfortunately our society assumes proper parenting can be provided in the nuclear family setting. We are reluctant to reconsider this premise, preferring to blame and intervene rather than support. This is a reality that makes it difficult to raise children. For those trying to raise children affected by prenatal exposure to alcohol, the task must be monumental.

The Value of Child Care

To understand fully this concept of caring for children, let us side step for a moment and look at the value society places on caring for children. "Caring refers to the mental, emotional, and physical effort involved in looking after, responding to, and supporting others" (Baines, Evans, and Neysmith, 1991, p.11). In our society women are still by far the primary caregivers. This is true whether we look at a woman's role in looking after children, caring for the elderly, volunteering, nursing, social work, or teaching.

Women and Caring

The task of caring for children, for nurturing children, is for the most part relegated to women. There is a presumption that women have an innate predisposition to nurture. It would be more appropriate to say that women have been socialized to think of themselves in terms of being the gender that nurtures, mothers, or cares for those who are not able to care for themselves. The pattern of women caring for and nurturing children can be seen throughout the years, but never so plainly as within the developing years of industrialization. As industrialization began and work moved away from the home, men went off to get jobs (became the breadwinners) and women stayed at home to care for the children. This was thought to be the way the nuclear family would function best. Women were left feeling obligated to maintain this role in society, they felt undervalued since men's work brought in the monetary gain and their work at home was left unrecognised. They felt isolated from the social world as they were left behind to care for the children (Guberman, 1990, p. 72; Forna, 1998, pp. 36-37).

This separation of gender roles has changed very little in recent years. We do see many women taking on a wide variety of jobs and positions in society but the majority of these paid positions still consist of minimum wage, or close to minimum wage, jobs caring for the more vulnerable in society. Men still hold the majority of the powerful positions in politics and big business.

Of the women who have paid positions outside the home, the majority of them also have the major responsibility for children or for the elderly living in their home. Women have found themselves a place in the larger society but again at a huge cost. They now have two jobs but are still being paid for only one. A large part of "women's work" remains invisible and undervalued (Miedema, 1999, pp. 84 – 85).

A mother's role is to see to the proper upbringing of the children so they will become responsible active members of society. The female homemaker's duties are geared

> towards consuming (rather than producing), maintaining the health and well being of family members, socializing children to their proper adult roles, caring for the sick and aged and overseeing the maintenance of the household. Despite changes in the definition of women's economic role, the family ethic has throughout history, placed women in the home, subordinated to men (Abramovitz, 1988, p.3).

We place the total responsibility of socializing children on mothers. They are expected to hold the line against any and all negative influences. Children are exposed to and highly influenced by teachers, extra-familial caretakers, relatives, friends, neighbours, police, fire fighters, salespeople, social workers, doctors, the media and strangers on the streets. Yet women alone are held largely accountable for any failures in socialisation:

> We would be naïve were we to fail to recognize the impact of television...Yet we persist in our moral overload on mothers; our expectations are unrealistic and we often become punitive when we are disappointed. Causation is not clear here. Are mothers oppressed because they are women, or are women oppressed because they are mothers (Meyer, 1985, p. 252)?

Caring for Individuals with FAS/FAE

We should expect then, when we encounter some of our most vulnerable children with FAS/FAE, the mothers caring for them would be overwhelmed. Biological mothers struggle with both the low value society places on caring for children and the added burden of guilt. Not only does society look down on individuals with addiction problems, but also points the angry finger of blame at them for bringing a child into the world that is going to have ongoing disabilities. Members of society generally feel that the mother could have easily prevented this from happening by not drinking during the pregnancy. This attitude shows little regard for the genesis of their problem and the acknowledged difficulties faced in overcoming an addiction problem. The pain and despair faced by many marginalized women struggling with addictions is unbearable without the numbing effect of alcohol and drugs. The task of dealing with this guilt, of fighting for sobriety, of finding a means to deal with the issues that lead to alcohol misuse is a major undertaking. Added to this are the disabilities that a child with FAS/FAE presents both in behavioural and cognitive deficits and the perpetual struggle to access necessary resources. It is little wonder that a large majority of children affected by FAS/FAE come into a substitute care arrangement.

The reality for children who live with biological parents who continue to consume alcohol is not encouraging. There has been considerable research over the past four or five decades about the impact that this environment has on children. Winokur and Clayton (1968) indicate that alcoholic fathers were more likely to physically or sexually abuse their children, whereas alcoholic mothers more often abused or neglected their children. "Children raised in alcoholic homes often develop emotional, psychological and/or behavioural problems as the result of unstructured, chaotic and sometimes abusive family environments" (as cited in Brown, 1988, p. 15).

> The literature (Beletisis & Brown, 1981: Cork, 1969: Black, 1981: Sixas, 1979) describes the alcoholic family environment as one of chaos, inconsistency, unpredictability, unclear roles, arbitrariness, changing limits, arguments, repetitious and illogical thinking and perhaps violence and incest. The family is dominated by the presence of alcoholism and its denial (Brown, 1988, p.27).

Kelley states that the combination of the characteristics of drug-dependent mothers and drug-exposed infants places these children at increased risk for abuse and neglect. Babies have sleep disorders, are sensitive to touch and are irritable. The mothers often feel guilty about whether their lifestyle has effected the baby, have little knowledge about the difficulties the baby is experiencing and have too high expectations for the baby. This is a dangerous combination (Kelley, 1992, p.318).

The usual alternatives to remaining with the biological parents are for children to be placed with extended family or to come into the care of a child welfare agency through apprehension. Occasionally children are moved straight into an adoptive family. Sometimes children are apprehended at birth and immediately come into care. Often, however, child welfare agencies, that are geared to protect children rather than support families, do not become involved until abuse or neglect has become critical. By this time the child is a toddler or pre-schooler. The combination of the effects of prenatal exposure to alcohol plus the unhealthy environment has often resulted in a very damaged child who is difficult to manage.

Streissguth et al., in their study on 61 adolescents and adults, as noted above, found that the individuals had very unstable, disrupted environments during the critical years of childhood (Supra at p. 2). When children are taken from, or given up, by biological parents, substitute caregivers are sought. Much of the time this means foster care. There should be little surprise that the majority of these caregivers are women. Consider the role of foster mothers. Meyer (1985) defines the role of a foster mother in these terms:

> To be a woman, to be a mother, to be lower middle class or poor, to be in a minority group, to work for (with? under?) a child welfare agency, to be paid a pittance, to be asked to parent a child whom no one else is able to parent, to try to love that child and to lose him or her when loving has been achieved, to be supervised by a 22-year old social worker, to have to deal with school teachers, police, courts, medical appointments, angry biological parents, and the impact of all of this upon one's own family – that is the lot and life of a typical foster mother in America. Any one of the status's mentioned would be sufficient to qualify foster mothers for victim status – that is, being a woman, a mother, lower middle class or poor, or a member of an ethnic minority – but when taken together they are, as is said, quite a lot on her plate (p. 252).

The foster mother is also often in a vulnerable situation. Her self-esteem, and her esteem in the eyes of the community, is tied to her abilities to be a "good mother", being able to parent effectively and bring up a "good child". This expectation is generally unrealistic as is discussed in Chapter 5 below. The foster parenting situation is generally far more tenable than the biological parenting situation, but it clearly requires an exceptional person with exceptional resources to manage the situations and stresses associated with "successfully" fostering a child with FAS/E.

If not foster care, children with FAS/E may end up with adoptive parents. Many, but certainly not all, adoptive parents come to the place of applying to adopt a child after a struggle to accept and grieve the fact that they are not able to have their own biological children. Being offered a child brings out tremendous excitement and anticipation. There may be an overriding feeling that "love can conquer all obstacles" when adoptive parents come face to face with the bright, shiny face of a young child. Katherine Davis Fishman (1992) views disrupted adoptions in these terms, "when adoptions come to grief, it is often from a disparity in expectations: either the parents expected something the child can't deliver, or the child delivers something the parents didn't expect!" (p. 42).

This is never truer than when adoptive parents have not acquired sufficient knowledge and skills to properly evaluate whether they can raise a child with FAS/FAE. Likewise, trying to raise a child that has not been diagnosed is the path to complete and utter frustration. As Diane Malbin (1993) states, "trying to raise a child with undiagnosed FAS is like to trying to get around Cincinnati with a road map of Denver. It's a good map, and it works in another city, but the streets just dead end, or end up in places you don't expect" (p. 253).

Research is showing that there are a number of key factors that can increase the potential for stable, nurturing environments for children with fetal alcohol. Adequate supports include a multidisciplinary approach. Children and families need medical diagnosis and services, educational understanding and practical classroom application, social services workers who can advocate for financial assistance and intervene in terms of counselling, support and crisis management (Zebroski, 1996, pp. 10-14).

All caregivers, whether they are biological or substitute, need to be able to access competent medical practitioners who are able to make accurate diagnosis and provide essential services to these children. Many children need a variety of medical services including eye specialists, speech and language clinicians, heart specialists, physiotherapists, occupational therapists, etc. In many locations these resources are not available. This makes the job of caring for these disabled children even more frustrating and challenging. Research shows very clearly, that early knowledge of the diagnosis helps the family "temper their expectations in accord with the emerging talents and disabilities of their child" (Streissguth, 1997, p. 175). When this early diagnosis occurs both professionals and parents can strive to meet the child's needs before tremendous, irreparable emotional damage has been done to a child who continually feels that he is not good enough and cannot live up to expectations.

Specific knowledge about, and ongoing training on how to, care for children affected by prenatal exposure to alcohol is also essential. Basic parenting techniques and behavioural modification have not been found to be all that successful. A more child specific approach which involves assessing the interplay between the child and his/her environment has been found to be much more successful. The family that understands the nature of FAS/FAE is better able to provide what their child needs. Predictable routines, clear expectations, and supervision beyond that dictated by chronological age are all necessary parenting techniques (Lutke, 1993, pp. 71 – 86; Shaskin, 1994, pp. 8 – 24; Warner, 1999, pp. 14 –25).

Parents need strong support systems and good self care practices while caring for children with FAS/E. A support group for caretakers of children with FAS/E is ideal (Wilton. Kessel and Clark, 2000, pp. 291-299). Parents need a strong supportive relationship with social service workers. Workers need to be knowledgeable about FAS and to serve as advocates in securing the necessary financial, medical, and educational assistance needed by these children. Most important, parents need to take care of themselves emotionally and physically. Caregivers and teachers become isolated, exhausted, and burned out. Families and teachers need to seek help in despair, feeling guilty for being angry with their children's/student's behaviour. They are often afraid of acknowledging how hopeless they feel as caregivers/educators. They are at a loss to know what do when all the tried and true methods that helped them parent and teach other children fail with these children (or make matters worse) (Caldweil, 1993, p.99). Because of the child's appearance of competence unknowledgeable professionals, and society often view parents in general, as overprotective or unduly rigid. Therefore, they need this ongoing supportive haven, to vent their frustrations about being misunderstood. They also can use their collective voice to advocate for better programs and resources for their children. They need to feel that they are not alone in their struggle, that there is potential for ongoing new and innovative ideas that may assist their children in maximising their potential.

The research in this thesis will take a look at the substitute caregivers in the Winnipeg and surrounding area to assess and evaluate the supports available. The study is designed to attempt to overcome any reluctance by caregivers to discuss the nature of their problems. It also seeks to appreciate both the context and the content of the caregiver's struggles. The present study seeks not only to determine where assistance and support are needed, but also where (i.e. in what context) it might best occur and what manner of approach will be most supportive to female caregivers of children with FAS/FAE. The study aims to go beyond this to understand what else may be needed or what other creative strategies this area may be able to find to assist these caregivers.

CHAPTER THREE

Methodology

Introduction

This qualitative research study takes an in-depth look at the work that substitute caregivers (women) provide to those disabled by prenatal exposure to alcohol. A review of the literature reveals that surprisingly little has been written from the caregivers' perspective. The articles, periodicals and other literature that have been published appear to contain mostly information about children with disabilities but not about the role of substitute caregiving itself. This lack of attention parallels the apparent lack of value we place on women's work as care providers.

I determined that qualitative research is the best way to approach this study. It provides the tools needed to derive a more complete understanding of the caregiver's role. Caregivers have the opportunity to describe and explain the many facets involved in their reality as those parenting individuals with fetal alcohol. They also have an opportunity to describe their reality in terms of the emotions, feelings and daily experiences that this caregiving generates.

Personal Worldview: Feminist Paradigm

In the first half of the 19th century, as industrialization became more and more entrenched in our western societies, men left the home to go to work and women stayed behind to care for the children and household (Waerness, 1984: Finch and Groves, 1982). Research prior to the 1960's seldom explored women's perspectives and contributions to this emerging shift in societal values and beliefs. Their work was taken for granted. Women's lives, activities and feelings were largely overlooked. Women and their roles were described as understood by those doing research (mostly men) (Tomm, 1987; Anderson, Armitage, Jack and Wittner, 1990; Kirsch, 1999; Finch and Groves, 1982; Waerness, 1984). Waerness (1984) writes, "women were (and still are) nearly invisible to male social scientists" (p. 68).

Over the past few decades women have become more and more visible in the workforce. However, their jobs still largely revolve around the role of caring for others, i.e., nurses, personal care workers, social workers, teachers (Baines, Evans, and Neysmith, 1991, p. 11). In addition to this paid work, they continue to care for children and other dependent individuals within their homes. Women are still socialized to see this double duty as their role and responsibility.

When feminist researchers began to explore their world from a women's vantage point, different realities and ideas began to emerge. Morse writes, "the feminist research agenda is to fill the void of decades of social science research that has ignored women informants, women's work, women's roles, and women's contribution to society" (p. 221).

My belief system, values, and understanding of reality fall within a feminist paradigm. This feminist paradigm encourages me to do research in a way that women's voices and views can be heard and in a manner that will provide beneficial outcomes for the women involved.

As a feminist, I believe our reality as women has been created by social, political and economic structures that influence and shape our lives. At a broad level, women collectively share this reality, but at the same time, as individual women we each carry our own "reality". This individual reality is dependent upon such things as culture, economics, education, cognitive ability, life experience, etc.

I believe that the FAS/E challenge that society presently faces has shaped reality differently for a number of groups of women. It casts biological mothers (and especially Aboriginal biological mothers) in a particularly negative light as they are blamed for their addictions and the birth of children with FAS/FAE.

It casts foster and adoptive mothers in the role of 'super moms' who are expected to provide children with FAS/FAE with everything thing they need in spite of little remuneration and a lack of adequate resources.

It casts social workers (who are mostly women) in the role of experts who are expected to both pass judgement on the opinions of foster and adoptive mothers and to deny them resources even when they feel the resources are both appropriate and necessary because it is the bureaucrats (mostly men) who have the ultimate decision making power.

Theoretical Framework

Kirsch (1999) explains that feminist research emerged out of the concern that research was being conducted "*on* women and was not necessarily beneficial *for* women" (p. 1). Feminist research takes a closer look at women's place within society by seeking out their voices. Hearing directly from the lived experience of women helps researchers understand how women's expanded roles and responsibilities are being managed, how women continue to be exploited and how to assert a position that will bring about more equality and health to women's lives. Kirsch says that feminist research is distinguished from other methods of inquiry by "its deliberate focus on gender combined with an emphasis on emancipatory goals" (p. 7). In other words, feminist research goes further than just hearing and listening to women's views and voices, it then takes on an action position. It seeks social justice for women through policy or action frameworks (Eichler, 1988, p. 68).

Cook and Fonow (1991) outline four general areas that distinguish the feminist approach to research from other approaches. These four areas are fundamental to my paradigm. I will outline them here with an emphasis on how they are important in light of the research carried out in this study.

First is reflexivity; "by reflexivity we mean the tendency of feminists to reflect upon, examine critically, and explore analytically the nature of the research process" (Fonow and Cook, 1991, p.2). This particular process is not unique to feminist research, but its emphasis on looking at issues from a women's perspective and what that perspective implies, is unique to feminist research. By this I mean, that in the past we tended to take for granted that women would care for those who were unable to live independently. We are now beginning to realise that this expectation that women will be the care providers is exploitation. Society, as a whole, needs to find ways to look after and care for those who are not able to look after themselves. I will be examining this research question with an eye to whether women are being exploited by taking on the task of caring for this population group by not being given such things as adequate knowledge, services, recognition or remuneration.

Action is another feature of the feminist approach to research (Fonow and Cook, 1991, p.5). In this research study, I interviewed the caregivers of persons affected by fetal alcohol exposure with the intent of going beyond what the reality of caring for this population is, to looking at what needs to change. This could mean changes as broad as a shift in societal attitudes about care giving itself, to more practical changes such as additional services, more knowledge, or changes in existing services. As a result of my findings, I intend to look toward a plan of action.

A third "feature of feminist epistemology is its refusal to ignore the emotional dimension of the conduct of inquiry" (Fonow and Cook, 1991, p.9). I believe that we cannot adequately know the "reality" of caring for individuals affected by prenatal exposure to alcohol unless we hear the struggles and the joys of those caring for them. Without this direct knowledge it would be impossible to have an in-depth understanding of what services or support would be most encouraging and effective. This perspective insists that the emotional experience is essential in understanding the caregiver's reality. It is this emotional piece, that can be so demanding and overwhelming that brings us a closer understanding of just how valuable this work really is. However, it can also lead to the danger of the researcher becoming overwhelmed by the story of the participant to the point of losing the objective of the study or trying to rescue the participant.

Lastly, "the feminist approaches to research are often characterised by an emphasis on creativity, spontaneity, and improvisation in the selection of both topic and method (Fonow and Cook, 1991, p.11). "Everyday life" is often a common theme for research by feminist theorists as they struggle to make sense of the world around them. In this research project, I attempted to study the daily role of the caregiver of the older adolescent/young adult as they struggled to assist and understand the needs of these individuals. I wanted to draw out the creativity, spontaneity and improvisation of those caretakers. I allowed for this by providing a somewhat flexible interview schedule. This allowed me to conduct each interview in a way that allowed for basic questions to be explored but at the same time gave the women an opportunity to tell their story in their own way. It attempted to give the participants a level of control in the process of defining their own reality.

Qualitative Research

The qualitative research approach was used for the purpose of this study because I wanted to capture a more in-depth understanding of a woman's experience in caring for individuals with FAS/FAE. I strove to capture the "reality" of these women. I wanted to give voice not only to the "cold hard facts" of how many care providers are looking after these persons, what questions and problems they experience, and what services might be helpful and relevant, but also to give a voice to the questions the caregivers think are relevant, what answers they perceive, what will encourage and what will dishearten them. In short, I sought to hear from them the joys, the sorrows, the struggles and the hopes, which form part of their experience. Tutty, Rothery and Grinnells' (1996) definition of qualitative research states well the process that I followed. The qualitative approach:

> Aspires to understand people and their social environments in ways that are as close as possible to normal human experience by studying them in their natural settings. It uses data collection procedures and techniques that try not to distort the experiences it is attempting to illuminate. It seeks to understand the information people share with us without insisting that it be reduced to numbers. And it does not require that information be squeezed dry and juiceless by an indifferent machine with the power to conduct sophisticated statistical manipulations but totally inept when it comes to appreciating the place, in human affairs, of uniqueness and nuance (p. iv).

Kirby and McKenna (1989) suggest that research has, and often is, conducted in a way that seeks to "explain and justify a world many are actually interested in changing" (p. 17). Researchers often are trained and hired by those in power to present a particular point of view. This method of maintaining the status quo has contributed to the silencing of those who are oppressed and marginalized. It leaves them with little opportunity to influence social structures and policies. The qualitative research method, however, can be used by not only "expert" researchers who have financial backing and means, but by any researcher who is seeking to understand and explore reality from any social or economic standing within society. Many of Kirby and McKenna's concrete suggestions for process and analysis have guided this qualitative research study.

Quantitative research "accepts that there is a reality independent of what we believe" and attempts to prevent our beliefs from "tainting" our perception of that reality. To obtain this objectivity, they use a "once removed" position in research (Tutty, 1996, p.8). In other words, they do not personally interact with those being researched, because emotions, opinions and personal bias would "taint" the results of their research.

Qualitative research posits that there is no absolute reality, that the reality we perceive is fluid and differs from ethnic group to ethnic group, city to city, community to community, focal group to focal group, individual to individual. Our perception of reality is dependent upon our life experience, our understandings, our relationships, etc. "The traditional positivist criteria of internal and external validity are replaced by the terms trustworthiness and authenticity" (Denzin & Lincoln, 1994, p. 100).

Unlike quantitative research which is able to generalise findings to larger populations, qualitative research instead tries to understand in-depth the individual experiences or realities of those with whom they interact. This is not to say that qualitative research denies there is a commonality in the realities of those being researched, only that it is not the emphasis of the research. Understanding the way a majority of the population believes and finding ways to meet their needs is an important endeavour (Tutty, 1996, pp. 9 & 10).

Another characteristic of qualitative research that makes sense for this research study is the flexibility of questions and responses that it allows. Qualitative research allows the participants to relate their unique experiences in a narrative form. This enables them to freely express themselves and also gives them a measure of control in directing the researcher both to the relevant questions and the relevant answers (Tutty, 1996, p. 11).

Another facet of the qualitative research method fits well for the intent of this study. Qualitative research is primarily inductive. An attempt is made to hear each persons experience in relation to the "subject" under study. At the outset, each person's experience is expected to be unique. The researcher attempts to approach the participant without preconceived bias. Theory is generally developed from the research, not vice versa (Tutty, 1996, p. 12).

Interpretative Phenomenology

Phenomenological approaches to research analysis "examine how human beings construct and give meaning to their actions in concrete social situations" (Dinzen & Lincoln, 1994, p. 204). Holstein and Gubrium state that, "The relationship between perception and its objects is not passive. ... human consciousness actively constitutes the objects of experience." The basis of this approach is that the world we all experience is "produced and experienced by members" (1994, p. 263). In other words, it is our experience and processing of knowledge that creates our personal reality. Reality is always being actively processed.

We come to understand and know our world through what Schultz, in Holstein and Gubrium, (1994) call "stocks of knowledge". "Stocks of knowledge are resources with which persons interpret experience, grasp the intentions and motivations of others, achieve intersubjective understandings and co-ordinate actions" (p. 263). These stocks of knowledge make our world familiar and from this familiar world, we make generalisations that help us understand our experience.

Holstein and Gubrium (1994) posit that language is our tool for shaping and interpreting meaning and thus "reality". "...We assume that others experience the world basically in the way we do, and that we can therefore understand one another in our dealings in and with the world. We take our subjectivity for granted, overlooking its constitutive character" (p. 263). The aim is to develop a social phenomenology, which will "interpret and explain human action and thought" (Ibid).

This approach matches the goals of my research. My hope is to try to understand the women's reality (which may well not be either my reality or the policy makers' reality) in order to explain and interpret it to others with the hope of some outcome in the form of social response. Patricia Benner explains the role of the interpretative researcher in this way:

> The interpretative researcher creates a dialogue between practical concerns and lived experience through engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds. The goal is to study the phenomenon in its own terms (Husserl, 1964), and this requires being critically reflective on the ways that any one set of prescribed methodological strategies, personal knowledge, and social context create a theoretical and perceptual access that influences understanding (1994, p. 99).

Through the interview process I hoped to begin to enter the caregiver's world, to imaginatively dwell in their reality. This approach also blends well with my ontological/epistemological viewpoint that one can only understand another's reality by being in dialogue with them.

The process I followed in doing this research involved first of all securing a base of women to interview. After this interviewing process was complete, I analysed the transcribed interviews through the use of hermeneutic analysis. Hermeneutics is the art of interpretation (Leonard, 1994, p. 56). Leonard explains hermeneutics as a circular process that involves all the aspects of the researcher's "forestructure", that is the researchers' prior knowing, prior opinions and prior critique (1994, p. 57). This forestructure is in continual competition with the data being revealed in the interview process. The interaction between the inquirer and the respondents will have an outcome that incorporates values of both. It will be an interpretation that hopefully takes into account as much as possible the biases of the inquirer and that accounts for the many influences that the respondents bring to the interview such as culture, economics, biological/adoptive/foster parent, etc. This involves a very intensive amount of critical thought and "movements in understanding" (Benner, 1994, p. 101).

> Understanding is historical and must be understood historically. Thus the researcher keeps track of movements in understanding... Typically there are false starts, but a rejected false start is an advance on understanding. Writing is part of the intellectual work of doing interpretation: therefore, interpretation is best served if these false starts are captured in writing. Misunderstanding can illuminate the interpreter's own taken-for-granted background (Benner, 1994, p. 101).

Strengths and Limitations of Methodology

By using the qualitative research method I was able to use open-ended questions and dialogue which provided an opportunity for clarifying and exploring experiences in-depth. Because a face-to-face interview allows for more of a trusting relationship to form there is the possibility of having a richer understanding of the caregiver's perspective.

Using the phenomenological perspective means that there is no agenda, no preconceived hypothesis which allowed me to listen more closely to the participants and let them give me the reality of caring for persons affected by fetal alcohol.

The research participants were restricted to foster and adoptive families because of both the limitations of time and money for this study. Biological parents, with a number of different issues were not included. Both the small size of the study and the restriction to just foster/adoptive parents make it more difficult to generalise to the larger population. However there are some strong observations and understandings that can be drawn from this study.

The Research Study

Participants

The women I interviewed were either foster or adoptive parents of adolescents or young adults affected by prenatal exposure to alcohol. I interviewed nineteen women. The first interview was strictly a test run. Two other interviews were not used in the final analysis because one ended up being a biological mother even after the telephone screening and I found that another volunteer had only fostered preadolescents. All the other interviews were used.

Several different strategies were used in order to obtain the research sample. The first strategy was to gain permission from the Coalition on Alcohol and Pregnancy to access the last page of their survey, which was jointly developed by the Children and Youth Secretariat and the Coalition on Alcohol and Pregnancy in January of 1998. The last page is a form asking if any of the participants would be willing to set aside some times to do an interview (see Appendix 1). This method of collecting data was originally planned through discussion with Kathy Jones, the author of the FAS/FAE Survey and member of my thesis committee. I had been discussing the focus of my study with Ms. Jones because of my prior contact with her through the Interagency FAS/FAE Program. She told me that that she was writing the survey and we discussed adding the last page.

I originally wrote to the chairperson of the Coalition on Alcohol and Pregnancy (see Appendix 2) asking to be provided with the raw data from their survey and to have permission to gain access to those who had responded to the last page. After much discussion I was told that I could not have the raw data, but was provided with a summary that had been made available to the public (see Appendix 4). I was also told that they could not give me the returned last pages of the survey. Instead, they wrote a letter to the survey respondents who both cared for adolescents and/or adults with FAS/FAE and had responded with interest to participating in an interview. They asked these people to send a form back to them if they were still interested in an interview and gave them an outline of my research proposal (see Appendix 3). Eleven people responded. I was given these names and I followed up with them by way of a telephone call. I had interviews with all eleven of these caregivers. One was a birth parent, as noted above, and could not be used.

I also wrote to Mr. Ken Murdock, Program Director at Winnipeg Child & Family Services. It was my understanding that he had a database identifying adolescents with

FAS/FAE within the Winnipeg Child and Family Services system (see Appendix 5). I did not receive any information back from him.

Because the above processes did not produce a diverse enough sample of participants, (I only received responses from Caucasian foster/adoptive parents), I employed the snowballing process. That is, I both inquired from the participants themselves and from other professionals within the Child Welfare System as to whether they knew of any other women who might be willing to participate in an interview. From this process I was given seven additional names. Two of these were Aboriginal women and two were Metis. I asked the individuals who provided these names to me to first contact the women before I called. This was done to ensure that they felt comfortable about the interview process and had some idea ahead of time that I would be calling. In this way they would have time to think about whether they wanted to participate. One woman did not call back, but her husband did. He was willing to be interviewed but she was not. I decided not to proceed because my initial intent was to interview only female care-providers.

Once I had the names and phone numbers from the Coalition I contacted the women and asked if they were still interested in participating in the interview or if they had any questions about the interview I was requesting. Once they affirmed that they were still interested, we set up a time and place to meet. At the scheduled time we first went over the consent form (see Appendix 6), filled out the demographic sheet and then proceeded with the interview, which was audio taped. These audiotapes were transcribed as soon afterwards as possible.

I also recorded, as soon as possible after the interviews, my reactions to the person and her story; my interviewing style and anything that I was surprised by or felt was significant. There were several reasons for this. It was an attempt to try to separate any of my own personal biases from the actual story that was being related. It also alerted me to anything in subsequent interviews that I needed to guard against, whether it was my approach or some additional communication techniques I needed to use in order to word the questions in a way that would bring out the maximum amount of information. On several occasions I found myself using questions that were quite leading. I also found that I was often interrupting when I knew or thought I knew what was going to be the ending to a statement being made. Many other reactions to the stories themselves were noted. These included such things as feeling myself being overwhelmed by the level of commitment these women displayed, being overwhelmed with emotion by some of the experiences that they had gone through, and feeling frustrated because I wanted to help, offer advice and continue to see them and offer support.

The Interview Process

I compiled a tentative interview outline. I then followed up with a pilot/test interview. I wanted an opportunity to see how lengthy the process might be, how the questions might be perceived, if they were worded in a way that captured the meaning behind what was being explored, if they were open-ended, etc. I found that the demographics part was somewhat confusing and that a few of the questions lent themselves to very short answers. From this feedback I completed both a demographic outline and interview outline that was used for the remainder of the interviews (see Appendix 7 & 8).

All of the interviews were conducted either in the homes/apartments of the women being interviewed or in an office building where I had previously worked. I was extremely impressed by the level of commitment from all of these women. There was not only commitment to their own children but commitment to assisting other children and care providers with strategies and suggestions about accessing services and finding creative changes in order to assist those effected by this disability.

Most of the women were very eager to tell their story. Some wanted to explain how special their children were, some wanted to vent about how their children had been poorly dealt with in one system or another, and others wanted to tell me about how they had been unfairly treated. Most wanted to try to participate in a process that might continue to bring the relevant issues of fetal alcohol disabilities to the fore so that those with the power and finances to make a difference would hear about what needed to change.

Many of the interviews were extremely powerful and emotional. I could not help but share some tears as well as many laughs and smiles. A number of people had heard or knew that I currently work for Winnipeg Child and Family Services and there was an observable unwillingness to say anything that might make them vulnerable. This was totally understandable and any time that it became apparent to me I would reassure them that this interview was totally confidential and was in no way going to be used to influence any decisions about subsequent care of other agency children. I also made sure that they knew the purpose of the interview, that it was not a promise for something better, but another piece that might be taken into account when requests for additional services/supports were being initiated.

As the interviews ended, I discussed how I would be using the information they provided. I told them that I would be transcribing and analysing the interviews and then erasing the tapes in order to ensure confidentiality. I also told then that no real names would be used in my thesis and that I would try to provide them with a copy of the findings. I also let them know that a copy of my thesis would be available at the University Library once it was complete. We also spoke about how this project would, in conjunction with all the other research being put forward about FAS/FAE, help provide ongoing information to the many systems involved with fetal alcohol effected individuals in order to bring about better service and support.

Analysis of Data

Process

The analysis process involved transcribing and categorising. I transcribed eight of the interviews and I hired an administrative assistant to transcribe the remainder. These transcripts were then printed and coded. Each interview was given a name and number in order to maintain confidentiality. An “identity file” as Kirby and McKenna (1989, p. 132) suggest was created which kept such information as the coding system, the date, time and place of the interviews, the original consents and demographic data.

Content and process files were also opened. These contained several copies of each transcript and the ongoing reflections I had made during the interview process. The analysis was done by hand rather than through the use of a computer program. A preliminary review of all the transcripts was done and highlights of the major themes were made in the margins. This provided me with an opportunity to refamiliarize myself with the transcripts as the interviews had been done over the course of several months. An attempt was then made to sort the information into the various important issues raised. The information gathered from the interviews, ongoing analysis of these interviews and the research questions set out in the thesis proposal were cross referenced. This was done through the use of labelled individual file folders. Each folder was labelled with one identified issue. After all of the information was reviewed each "bibbit" (Kirby and McKenna, 1989, p. 135) was cut out and placed in as many folders as relevant. This was a large task and many folders were started.

The next step was to look at the many file folders with their many categories and sort them into common and useful themes. After several attempts a workable set of themes arose with various relevant subtitles falling under each theme.

The final result is a look at the phenomenon of caring for persons with FAS/FAE. It is the interpretation of the combined experience of these sixteen care providers and my analysis of this experience, which is biased by my own experience and worldview.

Reliability and Validity

"Reliability in qualitative research has to do with description and explanation, and whether or not a given explanation fits a given description" (Janesick, 1994, p. 216). Kirby and McKenna explain reliability in this way. "Reliability refers to the trust or confidence we have when speaking about the description and analysis of our data" (1989, p. 35). In order to test the reliability of my research, I sought out a woman who could give some feedback to the question, "Would the women be able to see their experience in the research report" (i.e. is the information adequately & appropriately set out)? The woman who gave me this feedback was the same one who did the test interview. I chose her because she has fostered a number of children and she has adopted a child with FAS who is now an adult and has been through many challenges while caring for her. She is also a social worker who worked for many years as a foster care social worker and who now provides supervision to a team of foster care social workers. She is also a dynamic speaker in providing orientation and training to foster parents and social workers.

Another reliability check that I used was to compare my findings and major themes with those utilised in the findings of the Manitoba survey of needs regarding Fetal Alcohol Syndrome/Effects done by the Children and Youth Secretariat, the Coalition on Alcohol and Pregnancy and Community Action Program for Children.

I also did some comparisons between the findings in Baukje Miedema's book, Mothering for the State: the Paradox of Fostering and the findings in my research. Although her interviews with foster parents did not specifically address fostering persons with FAS/FAE, the results touched on a number of similar themes. For example, foster parents feeling that they did not receive enough information when a child was placed with them and foster parents wanting to be treated as "experts" when plans were being made for the children in their care.

According to Morse (1994, p. 230), validity in qualitative research is best determined by looking at the study in terms of adequacy and appropriateness of data, seeking verification through secondary informants and by use of an audit trail.

"Adequacy is attained when sufficient data have been collected that saturation occurs and variation is both accounted for and understood" and appropriateness refers to selection of information according to the theoretical needs of the study and the emerging model (Morse, p. 230). With this in mind, I interviewed care providers until I saw some repetition in the information being shared and confirmation that others being interviewed were also finding the same issues (needs, obstacles to care) to be a true experience for them.

I also used an audit trail. This process involves documenting the entire process of the study from its conception to its final conclusion. This not only included the raw data, but took into account my thought processes, prejudgements and biases. Morse states that the audit trail consists of "raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, materials relating to intentions and dispositions, and instrument development information" (p. 230). This process shows the logical progression of the study and validates that the conclusion is supported by the data analysis.

In summary, this study attempted to look specifically at the needs of those caring for adolescents and young adults affected by prenatal exposure to alcohol. I used a qualitative research model to gain an understanding of what caregivers are experiencing and listened to their voices in an attempt to understand what is working and what needs to change. My feminist orientation challenged the notion that the needs of this population group can be met solely by women, instead it sought to seek answers that looked at caring from a more integrated community approach.

CHAPTER FOUR

Findings: The Women's Voices

Research Baggage

I came to the interviews knowing, from my work experience, that individuals affected by fetal alcohol can be very challenging and that there are few services for teens and adults. But did not realise the extent of the commitment, the caring, and the sacrifice I was about to encounter. This research gave me the privilege of sharing, laughing and crying with some very strong, caring and committed individuals. I heard some stories that were not surprising and others that have haunted me. I often think of these care providers, and find myself hoping and praying that things are going well for them and their children and that they are finding support and strength to carry on.

I came with some preconceived ideas about the disability itself. When I have heard about children with FAS/FAE I often think things like, "this is going to be challenging, hopeless, society will never accept this person, they will never fit in". I had to challenge my own preconceived ideas about individuals with FAS/FAE not being able to manage on their own. Some do quite well. I came with these preconceived notions probably because in my job I often hear about the most challenging and difficult children since they are in need of the most attention. It was refreshing and helpful to hear that some young adults with FAS/FAE are doing well and finding happiness and acceptance in our society. Unfortunately, these were not the majority.

I came into this research project with a preconceived negative expectation that there would be a lack of resources for teenagers and adults, again, because of my work experience. It was good to hear that there are some services available for teenagers and young adults. However, the services available are largely only in place for those who are most visibly damaged.

One of my main struggles during the interviews was combating my desire to be a helper and advocate for either the foster /adoptive parents, the individuals with FAS/FAE or both. It was challenging to try and break away from my trained way exploring problems, breaking them down into manageable pieces and developing ideas in an attempt to problem solve.

I found that I connected better with some parents than others. Part of this was due to their personalities, and their approach to the interview. Another very large part of it was their attitude and philosophy about their children and their children's birth parents. I struggled with parents who tended to blame the birth parents for the problems or who downplayed the issues of racism, addictions and poverty.

The interviews reinforced my belief that as a society we have to educate ourselves more. This became much clearer to me as I heard more incidents about blaming parents (especially mothers) for their children's problems. I had heard this often in reference to birth parents but not as clearly about foster and adoptive parents. This blaming happens when we do not take the time to understand the issues and choose to blame the most vulnerable for our economic and social problems.

Demographics of Participants

The study included interviews with both foster and adoptive parents. Half of the participants were both adoptive and foster parents, six were solely foster parents and two were strictly adoptive parents. Caregivers ranged from age thirty-eight to age sixty. Twelve of the participants were of Caucasian descent, two Aboriginal and two Metis.

Six of those interviewed stated that fostering brought in anywhere from 25 to 100% of the household income. Six other participants said that they either did not foster (adoptive parents) or they did not factor foster pay into their income. For the remaining four, they felt that fostering income brought in only a very minuscule portion of their income.

Five of those interviewed were currently caring for one to four adolescent persons with possible fetal alcohol effects/syndrome. Three had one to two adult persons with FAE living in their homes. Six others were helping to support (financial, emotional) one to two adults with FAS/E in independent living situations (two up until time of suicide.) One care provider had one adult and three teenage fetal alcohol-effected persons living at home, and the last caregiver had two teens with FAS/E at home and was helping support another adult with FAE outside the home.

Nine women had received post secondary education, six had completed grade twelve and one caregiver had not completed high school.

Eight of the women had spent the majority of their adult years while the children were young working at home caring for the children. They had occasional casual jobs prior to having children or after the children were school age but the majority of the time was spent in the home. Two of the women had spent most of their time working from their home. They were self-employed through artistic or musical careers. The remaining six female caregivers had spent the majority of their time working outside the home either on a part or full time basis.

Five of the caregivers either are presently living outside the city limits caring for adolescents or adults with FAS/E or were living outside the city limits for the majority of the time these persons were children. The remainder live in the city of Winnipeg.

Profile of Caregivers

Nineteen women were interviewed over a period of seven months (April 1999 to October 1999). The first interview was a test interview to ensure that the questions, demographics, equipment, etc. was in good working order. This interview is not included in the data. One interview, despite a pre-screening call turned out to be a biological parent and although it was a pleasure to talk with her, it could not be used in the analysis. A third interview was also excluded because the child focused on in the interview was an eleven year old (a pre-adolescent) and not in the scope of this research.

Two of the interviews included the presence of the male partner, one of whom added much information to the interview. I did not ask this male caregiver to leave, as it was very apparent that they worked as a team caring for these children. The other male partner was only present for part of the interview and did not add much by way of discourse. A final interview was requested but the researcher was turned down because only the male partner was willing to be interviewed. It was noted, in at least five of those interviewed, that the male partner provided some support and parenting to the children with FAS/FAE in their home.

Some technical difficulty was encountered during the third interview. The tape recorder was not turned on for most of one side of the tape. This was not discovered until a few days after the interview when it was being transcribed. As a result I called the care provider back on the telephone and explained what had happened. She was very gracious and understanding and allowed me to return a few days later to re-interview her on the parts I had missed.

Angie

Angie is a foster, adoptive and biological mom. She has three biological children, has adopted three children and is presently fostering five children. One of the adopted children has FAE and Angie continues to provide some financial, emotional, baby-sitting and supervisory support to her. Three of the children she is presently fostering have FAS/E. She lives with her partner and has fostered for thirty-one years. She adopted her first child thirty years ago. She is a Caucasian woman who adopted an Aboriginal child. Her adopted child has no official diagnosis, but the foster children do have diagnoses.

Betty

Betty is a foster, adoptive and biological mom. She has one biological child, one adopted child and presently fosters three children. Her adopted adult child has FAS. She provides some financial support to her. Two of the foster children she is caring for have FAE. She lives with her partner and has fostered for thirty years. She has been an adoptive parent for twenty-one years. She is a Caucasian woman and has adopted an Aboriginal child. Her child with FAS was diagnosed at the age of nineteen.

Connie

Connie is a foster parent and has one biological child. She is presently fostering one child but has fostered several other children in the past. The foster child with FAS that she speaks about in her interview has moved into a supported living situation. Connie lives with a partner. The child with FAS she speaks of was diagnosed as an infant. She and her partner are Caucasian foster parents and they fostered an Aboriginal child with FAS. She has fostered for ten years.

Darlene

Darlene is a foster, adoptive and biological mom. She has one biological child, two adopted children and has fostered many children. She is presently supporting her adult daughter with FAS who returns home when other arrangements fall through. Darlene and her partner are Caucasian parents who adopted a Native child. Her daughter was diagnosed at fourteen years old. Darlene first fostered thirty-three years ago and has been an adoptive parent for twenty-seven years.

Edna

Edna is both a foster parent and a biological parent. She has one biological child and is presently parenting one teenager with FAE. Another teenager with FAE just moved from her home as he was too disruptive to the family. Edna lives on her own but has ongoing support from both her former partner and her biological son. She is a Caucasian parent fostering Caucasian teenagers. The teens had no official diagnosis. She has been a foster parent for six years.

Fran

Fran is a foster, adoptive and biological parent. She has two biological children and one adopted child. She is presently fostering three children, two of which are teenagers with FAS. She lives with her partner. She is a Metis parent fostering Aboriginal children. Her oldest foster child, the one most discussed in her interview, was diagnosed at eleven years of age. She has been a foster parent for seventeen years and an adoptive parent for eight.

Gail

Gail is both a foster mom and a biological mom. She has two biological children and currently has one foster child and one foster adult with FAS living at home. Gail lives with her partner. She is a Caucasian foster parent caring for an Aboriginal adult with FAS. Her foster adult was diagnosed at seven years of age. She has fostered for fifteen years.

Hanna

Hanna is a biological parent and a foster parent. She has three biological children and currently cares for one adult with FAS in her home. She lives with her partner. The adult with FAS never received an official diagnosis. Edna has fostered for thirty years. She and her partner are Caucasian foster parents who look after an Aboriginal adult.

Inga

Inga is a biological, foster and adoptive mom. She has three biological children, and three adopted children. One of her adopted children is presently living at home and has FAS. She also has three foster teens with FAS/E. Inga lives with partner and has fostered for twenty years. She has been an adoptive parent for nineteen years. She and her partner are Caucasian foster parents and have adopted an Aboriginal child. A doctor diagnosed her daughter with FAS at approximately the age of six.

Jane

Jane is both an adoptive and biological mom. She has two biological children and two adopted children. The adopted children are adults now and one has FAS and the other has FAE. She continues to provide some financial and emotional support to the adopted child with FAS but the adult with FAE lives on his own. She lives with a partner. She has been an adoptive mom for twenty-six years. Her child with FAS was diagnosed by genetics at the age of nineteen. The adult with FAE has never been officially diagnosed. These are Caucasian parents parenting Aboriginal children.

Karen

Karen is an adoptive and biological mom. She has one biological child and three adopted children. One of her adopted children had FAS and committed suicide in his early twenties. Her two other adopted children have FAE. Karen continues to provide some support to her adopted adult daughter with FAE. She lives with a partner. She has been an adoptive parent for twenty-nine years. A psychologist diagnosed the children in their teens. She and her partner are Caucasian parents who adopted two Caucasian children and one Metis child.

Linda

Linda is an adoptive and foster parent. She adopted four children and has fostered several. One of her adopted children committed suicide in his early twenties. He was diagnosed by genetics as FAE at the age of fifteen. Linda fostered for seventeen years and has been an adoptive parent for twenty-six years. Linda and her partner separated when her oldest son (the one who committed suicide) was in his early teens. She single parented her children after that time. She is a Caucasian woman who adopted an Aboriginal person.

Mable

Mable is a foster parent and biological parent. She has three biological children and has fostered many children. She currently provides support to two adult former foster children, both with FAS/E. She lived with her partner during the fostering of these children (recently deceased). The oldest one was diagnosed with FAE at the age of eleven by genetics and the younger one was already diagnosed with FAS when he arrived at her home when he was fifteen. She has been a foster parent for twenty-five years. She is a Caucasian parent who fostered one Aboriginal child with FAE and one Caucasian child with FAS.

Nancy

Nancy is both a foster parent and a biological parent. She has three biological children and has cared for several foster children. Currently, she still provides some emotional and financial support to a young adult with FAE who she formally fostered. She is a single parent. The young adult she offers support to has not been officially diagnosed. She is an Aboriginal foster parent caring for an Aboriginal child.

Olga

Olga is a foster and adoptive parent. She currently cares for two adult individuals with FAS in her home. She is a single parent. Both of her children were diagnosed prior to the age of five. She has been a foster parent for nineteen years, and an adoptive parent for fifteen years. She is Metis parent caring for Aboriginal children.

Paula

Paula is a foster, adoptive and biological mother. She has had five biological children, has adopted one child and is currently fostering five children. She currently cares for four teenage children with FAS/E and provides some support to a former foster child with FAS/E who is now an adult. She lives with her partner. None of the children were formally diagnosed. She and her partner are Aboriginal parents caring for Aboriginal children. She has been a foster parent for nineteen years and an adoptive parent for sixteen years.

The Individuals Effected by Fetal Alcohol

The individuals that the above care providers have parented differ both in age and disability. The age range is from fourteen to twenty-eight and their disability levels range greatly as well. Fetal alcohol has touched them all differently; some it has left mentally challenged, others with extreme impulse problems, others with no long-term memory, and others with combinations of these and other disabilities. Some have been diagnosed through genetics, others have been diagnosed by psychologists or other medical professionals and some have not been formally diagnosed but the care providers have listened and read about the disability and feel that the diagnosis fits.

Most of the interviews focused on one or two of the individuals with Fetal Alcohol Syndrome or Effects that these care providers parented. However, it is difficult to accurately say that only sixteen or eighteen individuals with FAS/E are represented in this research because the care providers have a much wider and more diverse experience. As can be seen from their individual profiles many have parented or continue to support from one to four individuals with FAS/E.

The Diverse Faces of FAS/FAE

Introduction

In order to understand the experience of these caregivers one must first hear about the diverse ways that prenatal exposure to alcohol affected their children's lives. Many of the children exhibited multiple problems. It was difficult to know if some of the disabilities that accompanied the FAS/E were a result of the brain damage caused by alcohol exposure or whether they were genetic. Included in the sample was a Downs Syndrome child, a borderline autistic child and a child with a rare bone disease.

Early Signs

Much of the literature speaks about common signs of in utero exposure to alcohol in young children. Some more common signs include growth, facial and central nervous system differences, problems swallowing and sucking, irritability, difficulty bonding, "pixie like", thin upper lip, flattened mid-face, indistinct or absent philtrum, speech delays, tremors, slow developmental and head banging (Streissguth, 1997, p. 19 and FAS/E Support Network, 1995, pp. 6-12).

Most of the foster/adoptive parents noticed that there were difficulties with the child(ren) placed in their homes right away, whether the children were babies or came at an older age. Most of these moms had no knowledge of FAS/FAE. These children were placed with them in the seventies and early eighties prior to information being readily available.

However, they did notice differences and had ongoing concerns, sometimes right from the beginning. Inga recalls, “She was rigid, really stiff to hold, had a poor suck, didn’t make good eye contact”. Darlene noted similar things, “she didn’t like to be held, I had difficulties feeding her, I had to be in a quiet room.” Paula said, “ When he came to our place he was already nine months old. He cried continuously for three weeks. He couldn’t stop from crying – day and night. …He had already been in seven homes before he came to our place.” Karen, even though she didn’t have the language said that when her son came at 10 months she immediately thought “he looked like fetal alcohol because he had, he didn’t have a philtrum, he was very tight across here.” Linda said, …When he was 9 months old, and you held him he would bang, I had bruises, … he would be forever banging his head on my chest.” Fran found something similar, “…he would smash his head on the cement”. Jane found she had to teach her children “everything specifically hundreds of times – over and over and over and over.” Betty and Olga found that the children placed with them were quiet and withdrawn.

It sometimes took longer to recognize the signs of fetal alcohol damage in the children who had other medical disabilities. Differences between the typical signs of the children’s diseases and the effects of alcohol took longer to sort out. Mable notes, “It took a long time to figure out because he was medically quite ill”.

Early Years Through to the Teen Years

Concerns about their children’s difficulties persisted and intensified as the children grew, entered school and reached adolescence. Many, if not most of the indicators of FAS/E that the experts such as Streissguth, Fox, and Abel have noted were recognized and reported by the participants in this study. Streissguth (1997) reports that the most common signs at this age are: attention impairments, learning disabilities, arithmetic disabilities, specific cognitive disabilities, deficits in higher order receptive and expressive language, and poor impulse control (p. 19).

Karen expresses the frustration of not knowing how to assist her child with ADHD.

> He could pass anything if you kept him isolated, but he couldn't cope with the stimuli of the noise and the children around him. Like we knew that he was, we knew that he was hyperactive and then we knew that he was attention deficit. And I believe, I tried lots of things like the Finegold diet where you remove additives and um, you keep him away from sugars and refined sugars as much as possible, but it was impossible and um, I remember once at five years of age he had um, a severe allergic rhinitis and he was on a medication called Talvest and he became suicidal on it and that was, I guess the first inkling of that potential. .... We tried him on Ritalin for a while, and it really did nothing but it depressed him.

Mable remembers her son:

> He got so that after four or five years he could make his lunch on his own and he would ask advice on choices sometimes. But he would get easily distracted making his lunch and he would go down and start fixing his hockey car and then he would think, o yeah, I have to have a shower and he would start that and the lunch was still be on the counter and...

Others had never been given information that this might be a problem for their child. Fran says that it was never questioned but that she remembers "he couldn't focus, so they started labelling him as a behaviour problem."

Inga says that she talked to a paediatrician about trying the children on Ritalin to enhance their attention span and decided to give it a try. "So we put them on a trial run of Ritalin to begin with, I think that is pretty common and it worked for one of them, it didn't work for a couple of others."

Linda said, "The doctor labelled him hyperactive, they wanted to put him on Ritalin at one time but I said no, I didn't believe in it." Hyperactivity, although not diagnosed in all of the children appeared to be a problem for the majority. A few others were quite quiet. Angie states, "Because in her case she was quite sedate. She was quite an easy child to look after in her younger years."

Another feature that reoccurred either in specific areas or in general, was the inability to retain information. Often it came up in the context of school. Darlene recalls. "Teachers, instead of trying to find out how she learned, seemed to be very irritated that she was stubborn, one day she knew it and the next day she didn't. And why would she tell me yesterday if she doesn't." Comprehension was a real difficulty. They could often read at a grade six, or seven level but comprehension was close to non-existent. In the context of writing exams, Betty recalls, "she couldn't pass because she couldn't retain the information." Jane relates a similar frustration,

> He wanted to get into Red River Community College and he had to have Grade 10 math to do it. We tried five times to get that math. I spent an entire summer at the lake just working on the math with him. And this was after he had done it, I think at least twice already. I could not get it into his head.

Another frustration for the caregivers was the difficulty in giving the kids instructions. Edna comments, "If I asked them to do two things they might get one done or they might forget both things as they were walking half way down the hall." Fran says she could say to her son, "you need to go upstairs and put your pyjamas on and I would go up there and he would be just standing in his room and I would say what are you doing? He would say well I am up here but I don't remember what you told me to come up here for."

Ability to generalise, impulsiveness, understanding consequences and an apparent lack of fear were several other behaviours that were mentioned by most of the caregivers. These four behaviours are all interrelated. They require the ability to think through behaviours to see what lies on the other side of the action. The children in this study did not have the ability to do this. Jane states, " I don't think that they have a sense of fear. They can't figure out what's going to happen. They don't even think that something will happen." Karen put it this way, "He rode a little tractor down the stairs, you know. I mean once wasn't enough. He would run across the street to play chicken with cars at the age of 2 ½ or 3." Linda recalls,

> We had a deck in the back of our house and it had like little steps leading down to the yard, and he would drive his tricycle down those steps. He did it over and over like you could not, ... I got my husband to put a board across, like a two by four so he couldn't lower his bike on the steps. Well he would just lift his bike over it and down the steps, head over kettle and he did it over and over.

Later on, she says,

> It seemed like as soon as the surroundings changed, he couldn't generalise. But I realised later that a lot of it had to do with he had no memory, he had no short-term memory. The psychologist said that he developed chains of behaviour in order to go through his day. Any change that disrupted this chain of behaviour that he had set up threw him for a loop because once that chain was broken he didn't how what to do or what was expected of him.

Nancy describes her son's quick admission to guilt with the police in this way, "And you see this is where, apart from that short term memory there seems to be a delay in processing consequences. He sees, how he feels at that moment, how he sees things at that moment he will react to." Mable said when her son "got panicked he would just walk around in circles. Cause he was almost too embarrassed to admit that he didn't know how to get himself out...." Hanna says, "Some of the areas that make her particularly vulnerable is she doesn't understand consequences. She can't learn from one situation and use that learning to generalise to another situation." Betty worded it this way. "...I'll say how come you ate all the candies and he'll say, no I didn't but the wrappers are in the garbage in his bedroom. You see, there is no connection at all." Angie describes her son this way, "He can't stop from taking everybody's pen. He stole the teacher's earphones from under his nose. The teacher came to the house looked at them and said, yep they are mine and thank you very much. You just have to take it with a grain of salt. He cannot help himself from stealing."

A number of care providers mentioned that there were developmental delays. Darlene recalls, "...she was delayed in everything. Speech, we, like it was more of a global delay, like she didn't talk until she was close to two, she didn't walk, she didn't sit up until she was almost a year, it was almost like she was where she was in size." As the children aged chronologically the developmental delay often became more obvious. Connie states that her daughter was chronologically 17, but "I would say she was about at a 5 or 6 year old level." Darlene words it this way, ...and although she is an adult, I would say she is 12, 13, or 14 emotionally and socially."

Several caregivers commented that their children didn't seem to have a normal sense of emotions. Angie stated, "What the school and myself have found is that there are no emotions, the sadness, the crying even. I have heard her crying and I try to figure out why she is crying and I have no idea." Karen recalls, "... he never laughed or smiled at anything. He would smile or laugh if he saw other people laughing and I think that carried on until he was 22 months..."

Others said that there were physical features that stood out. Olga says that her son is very sensitive to the light, he is almost blind." Nancy says when her son came to her at 14 " he was also small, ... but once he started growing he really grew rapidly." Karen says her son "was very good looking, but we had his jaw reconstructed at 15 or 16. He had a secondary malocclusion." Jane recalls that both of her children had "terrible, terrible teeth and very small jaws." Her daughter had "two rows of teeth at the top of permanent teeth." Linda says her sons "hands and feet were all over the place". She took him to the doctor and was told that unlike the average person "he had no walking pattern... he would fall going upstairs and fall going downstairs, he would fall on his bottom almost every morning."

Teen Years

As these children grew to be teenagers, either more problems emerged or the gaps in academic, social and emotional development began to become more visible causing increased difficulties with behaviour and relationships.

> Parental panic and confusion, professional uncertainty in the absence of clear diagnostic information, peer group pressures for independence, decreased interest in school as success diminishes, and normally developing adolescent sexuality all conspire to destabilise whatever equilibrium was developed during childhood. … Problems that teenagers with FAS/FAE face during this period are increased failure and less satisfaction in academic classes, more social isolation as per interactions are dominated by cliques, uncertainty or unrealistic expectations about what it means to grow up, and a looming sense of low self-esteem and depression. (Streissguth, 1997, p. 136)

Participants in this study certainly found the above to be true. Mental health issues such as suicidal tendencies and depression were noted by some of the caregivers who had higher functioning children. Karen talks of the painful events that led up to the suicide of her son "His probation officer said, 'well he has to go to prison because if psychiatry won't keep him, keep him safe, he is a danger to himself.' It was just horrible…. Now he was making actual attempts. And then, while he was in prison, he was finally successful."

Linda remembers, "… Around 13 he was seeing a psychologist and they put him on Prozac, which I didn't agree with. … But he did go through a suicide period where they thought it would just be easier because he got made fun of by his peers, so it was a very difficult time."

Self-doubt is often a part of normal teenage development but for these teenagers who were often misunderstood, put down and victimised, self-esteem was frequently shattered. Fran remembers her son coming home from school saying, "I'm just so stupid, I'm just so stupid." Karen recalls, "…by the time she hit high school she was so sick of being a resource kid she said I just hate being a resource kid and quit. Her self-esteem was shot."

Angie reflects on the foster children she has raised, "I don't even think about self-esteem for these kids. How can they have self-esteem a lot of the time with everything that is wrong? She is slow, she is this, she is that."

Karen tries to make some sense of the sexual victimisation that her son endured, "I think they are risk takers, they are risk takers and they are impulsive, I don't think they know what to do with sexual feelings. I think their low self-esteem is a factor." Jane relates a story about her daughter at the age of 19, " She got married to a fellow from Morocco whom she had met a week before who wanted to be a Canadian citizen… I mean this had no chance…." Olga states, "He was victimised again at the YMCA – somebody grabbed him in the shower." Darlene says, "although I didn't know about it at the time, she was being abused by her brother."

They also endure victimisation through scapegoating. Linda remembers, "He got to the point where he didn't even bother saying I didn't do it because they wouldn't believe him."

When adolescence hit, their behaviour sometimes became unmanageable. Their behaviour often displayed a lack of social skills, lack of anger management, impulsiveness, loneliness, and confusion over their sexual drive. These behaviours left some caregivers anxious, desperate and at times, numb. Jane comments,

> She needs a vast number of people to constantly be on the go so that she has somebody when she needs somebody; and she needs somebody NOW. …. I don't think she has any friends. …. That's one thing where

> people like that are very, very needy. I don't know how you ever solve that because they don't become less needy as adults."

Angie says, "They say he is likeable, people like him, but what happens is he can't keep a friendship. He moves from one friendship to another." Mabel explains, "it was mostly getting in with a bunch of kids that were probably the outsiders in the school system. …He was just so desperate to find friends that he was attracted to anybody that would take him in."

Angry outbursts were common with other children. Linda describes her son's anger; "… if he was scolded for something or if he tried, you know, was frustrated about something… he would just sort of go off and then you would find it destroyed…"

Darlene describes her daughter's lack of anger management, "…when someone made fun of her she would hit them. And so she got expelled for one day and three days and five days and it, you know, she would just say, fuck you and walk out." Gail describes her son's behaviour, "…and then he becomes totally uncooperative. He won't budge. You have to physically move him. And then he lashes out. Throws something or kicks, bites and spits."

Substance abuse sometimes became a problem. Karen comments, "I later found out, he told me too that he did his first line of cocaine when he was 12 or 13 in the school yard." Darlene remembers, "We would drop her off at school and they would call back 10 or 15 minutes later saying that she wasn't there. She tells me now that there was an old abandoned car behind that school and that was where they used to smoke and drink. She was about 12 then." Fran explains, "…he started drinking and doing drugs and then blamed his biological mother, she is making me do this cause if she hadn't been drinking when she was pregnant then I wouldn't be like this."

Several teens became totally out of control. Angie states, "...as she got into grade ten and that, she just went on the street and she even travelled across Canada to British Columbia and Alberta. Child and Family Services brought her back one time but two days later she went back." Paula says sadly, " ...we hung on to him until he was 17. And the spring of his 17th year, he started sneaking out at nights. And we just lost control."

Inga says painfully, "She took off and moved down into the Osborne St. area – no fixed address, just kind of sleeping wherever, with whoever. She did that for about a year and a half. ... Oh, it was the most devastating experience, I can't even imagine, ... now that it is over I think, wow, how did we ever live through that."

There was no means of dealing with the impulsivity in the teen years. Angie remembers, "You couldn't get through to her. It was like there was a mental block there. We couldn't keep her home at all, we couldn't do anything with her at all really." Many other foster and adoptive parents experienced a similar frustration. Darlene recalls,

> I honestly can say that from the time she was twelve to fifteen there probably, if there was any joy I can't remember it.... I remember one time, she had been, she would always say, Mom, I'm not going to run anymore, I have finally figured things out, and stuff. I remember sitting on the steps all one night so she wouldn't go out and then to get up the next morning and she said, 'look at this house, you don't even clean it up. There is a bag of garbage sitting here, jeez.' So she picks it up, this bag of garbage. It was winter and she was in her bare feet, so she went out the back door and she threw the bag of garbage down and she went running in her bare feet and there was a car of kids waiting for her at the back lane. We couldn't relax and have a cup of coffee..."

Karen also remembers the teen years, "He, um, got his grade ten math totally stoned. He went back to school when he was 17 or 18 and people put him in grade twelve and he was coping with that but then he went out and got drunk or did drugs or ran away again. "

Relationships were another struggle. Jane comments about her daughter's boyfriend. "He was very abusive to her. He wouldn't let her call home, and he didn't let her come home. That was very abusive and she tried at least three times to move out and eventually the police helped her to move out."

There were also problems with sexuality. Paula says, "The oldest boy, he was charged already for having touched the girl." Angie describes one of her sons, "He talks dirty all the time, how he wants to play donkey games and dirty games. ... All through his years he has done inappropriate stuff." Karen says, "...he got into, to support his drug habit, he got into prostitution. And I think there were men who were in love with him because we saw the letters, but he never really stuck to any one person. He picked up and drifted and used people I think."

For those children who were lower functioning, the teen years were less nerve wracking. Connie comments on her daughter's teenage social life. "She had friends in her class that she got along with very well, and my aunt has a daughter who has Downs Syndrome and they grew up together and they went to school together, and they were good friends." Gail describes her son's teen social life, "He likes getting out and doing things and I don't think it bugs him when it's just me who takes him bowling or when dad or my daughter stay with him. My youngest daughter started bowling with him in special bowling and they have a really good time together." Hanna puts it this way, "We've always taken her everywhere. If we go away for weekends, she'll come. She eats out in restaurants with us. She goes when we visit friends. We go on vacation – we rent a cottage in the summer and she comes with us."

Although there were many struggles and many questions throughout the teen years, the women in this research group showed a tremendous commitment to their children. Through all the troublesome and turbulent years they continued to support and advocate for their children.

Many reinforced what Anne Streissguth's research on secondary disabilities pointed out. "...home life (stability, nurturance, 'good quality') are universal protective factors for all Secondary Disabilities. This common sense protective factor is a fundamental right for the well being of all children." (1996, p. 64).

Angie comments on how hurtful a move would have been for their child. "...he's a handful, but if you sent him back, that would screw his life totally, just totally. It would be just like doing the worst thing in the world." Inga says, I think multiple moves are so, so damaging. And Paula comments when talking about some of the struggles they've had, "we hung in there so they could have a home". Betty believes it was the stability that made the difference for her daughter. "...believe me, there were many days that I could have called Child and Family Services and said come and take her away." (She stopped and showed me a scar and said it was from her daughter.) "I was just trying to hold on to her so she wouldn't do something crazy or hurt herself." Edna feels that there are two extremely important issues for these children. "Of course getting them into a good stable home where it is not a chaotic home is number one but then school is number two."

Adult Years

For those who are now adults, the transition for some has held its own struggles and knocks, for others it has been fairly smooth. For Betty and Inga, their daughters have found partners who are supportive and understanding. Both of their daughters have children of their own and are parenting well. There is still support from home. Betty says, " I have the baby's money. They don't have their child's allowance. It is sent here and goes directly to the bank so I control it and it is invested for the kids." Betty also says her daughter, "calls everyday" for support and advice. Inga says her daughter has had a baby, and "is a wonderful mother.... She needs supervision, she needs reminders about stuff, but she is an excellent mother. I'm so proud of her." For Connie, Gail, Hanna and Olga, and one of Mabel's children, they have transitioned well into adult services, they are lower functioning, and as such have visible disabilities that have made access to services a lot easier. Karen and Linda have lost their adult children through suicide.

The remaining caregivers are either waiting anxiously, fearing that there are few resources available to assist their children or hoping against hope that the late twenties and early thirties will not bring the end of another life but new maturity and another chance to make things work.

Streissguth (1997) identifies the most common difficulties for adult people with FAS/FAE. They include "money management, medical care, productive work, safe shelter, and a sense of community" (p. 138). The caregivers in this study reflect these struggles in their stories.

Angie lends support to her daughter who is both struggling to parent and in an abusive relationship. She provides all the support she can but wishes her daughter "had no children". For Darlene, whose daughter was 21 at the time of the research, life is still riddled with anxiety. In the early hours before the interview her daughter had called asking her to pick her up. She was drunk.

> So I told her no. At about 2:30 there is a call from the pay phone, I didn't answer. Then about 3-3:30 she shows up at the back door and says, 'Mom, I think I am in trouble. There is a guy in a pick-up waiting in the driveway. I didn't have any money to pay him for the ride, will you go pay him?'.... She said sorry about that and said she just wanted to go to sleep. Well, I didn't know what to do, I guess to be consistent I shouldn't have let her stay but I said okay and gave her a blanket. ...Then I went upstairs and lay there for an hour or so wondering is she smoking in bed is she doing this, is she doing that? At about 5:00 I got up and came down and she was sound asleep. So I said, okay now I can catch a few hours of sleep. So, I mean, that's the way our life is. ...Maybe the only way out is for us to go someplace where she just doesn't know, I mean, that is what I think on the worst days and you know, obviously we think that is not the answer.

For Fran who is looking at her son turning 18 within the next year there is genuine fear.

> I'm afraid for him, I'm very afraid. ...What happens when this kid turns eighteen? He is lost to the system and because of his alcohol abuse I am really afraid for him because people are really going to take advantage of him because he lets them, he doesn't realise a lot of times that they are taking advantage of him. I'm so afraid for him.

Jane speaks of her twenty-six year old daughter. "I think it would be very nice if she could somehow have some kind of a job so that she would feel as though she were a functioning member of society because I think sometimes she feels… Well, as she said to me just last week, 'I'm just a loser.' I don't want her to feel that she is a loser. I want her to feel that she is just as important. She is a human being."

Mabel wishes that her twenty-six year old could get a handle on his drinking. "I would sure like to see him, ah, get out of the rut that he is in and get a part-time job and able to feel good about himself and not be afraid to walk down the street". For Nancy and Paula it is the same. They see their kids living a transient lifestyle, abusing substances and without a job or a sense of well-being.

Racism

As well as being impacted by prenatal exposure to alcohol, the separation and loss from biological family and sometimes multiple alternative caregivers, most of these children had to deal with the cold reality of racism. The majority of the children were of Aboriginal descent and the majority of the caregivers were Caucasian. Many of the caregivers reported that the children had to endure a lot of teasing and unfair treatment. Angie recalls her oldest daughter being called the "drunken Indian on Main Street". Betty feels that her daughter "pulled herself in" because she was Aboriginal and didn't want to draw attention to herself.

Darlene recalls extreme racism in the small community where her daughter first attended school. She recalls her being separated into a group for slower learners. They called the group, 'the brown group'. "The brown group consisted of three other children that were in foster homes that were all Aboriginal or Metis."

Darlene's daughter felt this prejudice throughout her life. In her teens she experienced such things as being hit over the back with a cane when she was running to get into her mom's car that was parked by a bus stop. An elderly couple that were waiting at the bus stop saw her, a young Aboriginal women running toward them, and assumed she was going to steal the woman's purse. Darlene says, "she can't walk anywhere without someone assuming that she is a prostitute."

Her daughter has since obtained her spirit name and is learning much about the traditions of her people. Darlene and her partner struggle with the painful question of whether their daughter would have been better off with an Aboriginal family. They love her and support all her efforts in learning about her Aboriginal roots but still wrestle with whether she would have done better growing up in an Aboriginal home. One day, after coming back from a visit with her biological family up North, she said to her mom, "Mom, the best thing about living up North is waking up and everybody is the same colour as you, you don't know what that is like." Darlene says…so, she is lonely in that way too, it's not nice being Native in Winnipeg. "

Inga says that her daughter was the "only Aboriginal child in that school and that was extremely hard on her". Linda says that her son experienced prejudice from the day he started Kindergarten and was called a 'brown cow'. She said they were living in a small town and many parents there were "extremely upset about having Native children going to their school". Olga describes the prejudice as a "double whammy". Not only do her sons have to deal with their disabilities, but also the prejudice.

It is hard to determine, and certainly not in the scope of this thesis to analyse the impact of prejudice on the lives of these children. It is, however, certainly a strong force in their lives creating anger, lowered self-esteem and confusion.

Parenting

Introduction

One of the main foci in this research project was the caregiver role. Interviews were conducted in the hope that a fuller understanding of what this role entailed could be collected. What was their preparation? How did they access information and learn about the disability? What kind of strategies did they develop to manage to parent? What success did they have in accessing services? How was their decision to parent children with this disability accepted by family, friends and community?

Preparation

The question of training was put to all of the foster/adoptive parents in this research study. Many of these caregivers first began looking after these children in the seventies. Nine of the sixteen caregivers related that they had no training at all prior to having children placed in their home. Four of these said that it helped to have had day-care experience, nurses aid experience or experience growing up in a large extended family situation.

Five of the adoptive mothers related that they went either to a meeting or an orientation prior to having a child(ren) placed with them. Four of these mothers felt that it was very superficial. One of these mothers went on to push for Child and Family Services to provide more extensive orientations. She was instrumental in the present practice of holding an "older child" adoptive series of meetings that includes many topics such as attachment, FAS and the importance of embracing the Aboriginal culture when adopting an Aboriginal child. Another mother very sarcastically said that it was, "A few people fighting with the Agency over rules and regulations and that is about it."

The two foster parents who began fostering within the last ten years went to orientations on a weekly or biweekly basis for about six months. One of these foster moms who has only been fostering for the past six years is quite angry at the Agency for not providing training specifically on FAS/E. She had to use her own resources to go out and take courses to understand the children she was attempting to parent.

The only times that the children coming into the caregivers homes were previously diagnosed was when it was very observable like in Connie and Olga's situations or when the child was older and had been diagnosed while at a previous placement. Only three children were actually identified as having been diagnosed prior to coming to live with the caregivers in this research study. However, many of the children were placed prior to specific knowledge being available about this disability.

Apart from the lack of knowledge about FAS/E, caregivers felt there was an overall lack of information made available to them about the children being placed in their homes. Inga says, "I contacted the worker and asked her if there was any kind of family history that would give me a clue as to why she was behaving the way she was. They didn't have any idea whatsoever except the worker said 'that the mother was an alcoholic but that wouldn't have a bearing on anything.' " Edna remembers when she got her first children effected by prenatal exposure to alcohol:

> This was six years ago, no five years ago, and they hadn't been assessed really, ah, they had been in a receiving home for almost two years. So when I got them I thought I was just getting regular children and I found them very hard to deal with, very very hard and ...I don't understand why they didn't know they were dropping these kids off on me who was kind of a fresh foster parent. ...I had no information, no idea of the past baggage, a little bit saying that there was no control and they were misbehaving a lot and there were school problems and they were fighting and that kind of thing. Well, I thought that was like regular kids.

Connie's daughter came to her from her extended family so she was well prepared, "I knew her for a long time so I wasn't very surprised by the experiences we had."

Some experiences were inconceivable. Betty recalls, "Sometimes you got nothing. And like the one that is 29 now, when I got her... she came with a big file like this (spreads her hands wide apart) and they said this kid is crazy. So I had her for three days.... And I said, this kid is deaf, there is nothing wrong with her, she cannot hear."

Even when the realisation did come that a child in their home had FAS/E, access to information was often difficult to obtain. Fran expresses her frustration,

> So, I mean, *I* found the resources. I am not blaming the social workers because I don't know how far their hands were tied. What I am saying is that I think that when a child is diagnosed, then foster parents should be handed (clap), this is it, this is what you can read up, this is where you can find out more. So when it does get frustrating you can just look and

> say that is why he is doing this or that. I mean it took me four years to not get so frustrated with him. I mean, like there are days where he still frustrates me because its just stupidity with him, you know. Not to go on the street when a car is coming. I mean if I would have had some knowledge about what these kids suffered through being fetal alcohol, then maybe I would have understood a lot more...

Angie says that there was information coming out in the eighties about fetal alcohol effects, "But there was no where to go to learn more about it." Gail also comments, "And I know when our other foster son first came and he was Fetal Alcohol Syndrome, it's learn as you go. And even for our daughter who is now 11, if we would have had more knowledge... she came when she was only 2 ½ months old.... If we would have had more knowledge before they came.

Parenting Strategies

With limited information and knowledge about what their children were struggling with, why they couldn't process information, why their behaviour was so different, many of these foster parents found parenting strategies that made a difference.

Karen talks about learning to put boundaries and structure in place, "Certainly you have to be loving, but you, the boundaries need to be there and you need to be really firm about what they are." She also said that one of her son's teachers found a way to work with the children. To help "control the kids and contain their energy and himself too, at nine o'clock, they would jog around the school yard." Linda says,

> I knew he had trouble remembering things, so every time we went out in the car, with all the kids, we would do the times tables, we would recite them and then we would give them, take turns reciting them because we were like driving to Winnipeg all the time and its this hour drive and like

> over a course of four or five months he learned all of those and he remembered them because I guess we got it into long term memory.

Mabel says, "you have to be their exterior brain all the time. ... We had to constantly, you know, pick him up or send notes, and he would forget the notes, there just wasn't a day that went by without a screw up you know." Nancy says, " I work very hard to maintain one level at all times. ...It scares them or they back away from it if you raise your voice." Many others like Mabel learned that you had to "break commands down to one at a time." Darlene says that after trying and trying to get her daughter to memorise the timetable she

> finally thought, she is not going to get this, it is memorising and so what I started working on was things like you have twenty cents and you spend 10 on this, how much do you have left and she would say, dah, 10. She could figure out anything practical that she needed to. Now she is good with money, she rounds things off, and I taught her to do that. I said, you know what, taking 9.77 from twenty is difficult, don't even try. What is it closer to, 9 or 10 and she'll say 10. So you've got twenty and you take 10 away, you've got and she'll say 10. And so, I notice she'll say I get 100 bucks and I'll say is that what you get and she'll say, well, I get 113 but you have GST and PST and I'll say that's right. That is how she manages now.

Darlene also remembers going to the doctor and there being concerns about weight gain with her daughter. The doctor would say,

> all you have to do is feed her right, she just needs some good food in her. I just felt almost embarrassed always by that, I found that what worked best for her was to let her nibble, she would have her half of a peanut butter sandwich and half a banana and then a couple of hours later I would say here is some crackers and cheese and here, and I just kept giving her lots of little meals....

Hanna says,

> Our way was that you picked the behaviour that you could stand the least (the most disruptive) and you only deal with that behaviour. You ignore the rest. I will tell you it was very difficult with her because sometimes the behaviours she had (there were so many that were just socially unacceptable).

Supervision was something that most foster/adoptive parents found to be constant and absolutely necessary. This need for supervision embraced the entire life span. Inga remembers,

> …in her toddler years it was just constantly repeating everything….
> …and also supervision because she was kind of fearless and so… …we had a six foot locked fence which we couldn't keep her out of. She managed to scale it regularly so it was real hypervigilence when she was little, just the safety issues.

Jane comments, "I don't think anybody who has never had children with these difficulties understands how much constant supervision. For so many years, I mean for so many years, sort of a forever kind of thing. And how much energy this all takes." Hanna, in speaking about adolescents and young adults says, "I think they need to … certainly still have to be supervised – parents have to be more involved with them. You have to look out for them more – be more cautious about who they mix with, who their friends are. Try to direct them in those areas."

These strategies that so many adoptive and foster parents learned through trial and error are precisely the strategies that much of the current literature suggests as being the most effective ways to manage and parent children with FAS/FAE (Lutke, 1993, pp. 71-86; Shaskin (ed.) 1994, pp. 1- 24; Jim Slinn, 2000, 235 – 246; Janet Adams, 2000, pp. 261 - 268; Susan Doctor, 2000, pp 115 - 126). These parents and professionals speak of success for young adults occurring because they had people in their lives who became 'external brains' for the person effected by prenatal exposure to alcohol, (S. Doctor, 2000, p. 119) who provided critical support networks like the personal care assistant program as highlighted by (Janet Adams, 2000, p. 263), or had people in their lives to patiently supervise, provide structure and direct them as they became adolescents and young adults (J. Slinn, 2000, 241-242).

Emotions

Another very important factor in understanding those who have parented this specific group of children is the emotional aspect. For many it has been a roller coaster of emotions.

Many foster/adoptive parents found themselves being blamed for the struggles their children were having. Darlene recalls what happened when her daughter was in the Marymound locked setting group home. Darlene had been doing some reading about Fetal Alcohol Syndrome so she had asked if they thought that her daughter's prenatal exposure to alcohol might have impacted her. She was told "until you stop looking for excuses for her there is not going to be any improvement. I just felt like the worst parent". Hanna remembers the school telling her "You don't know what you are doing because we are the teachers and you are just the foster parent. We are the experts. If I hadn't been so stubborn… so we persevered and said, 'no, we do have some ideas.' Karen put her frustration very bluntly,

> Child Guidance Clinic at the school was absolutely useless. They are not well qualified for the job, they are not well trained and they do not listen to parents, they listen to the teachers at the school. You are judged and

> labelled and you are a regular pain in the ass as parents. I had one say, well if you would try and stop being super mom, things would be a lot better. I was glad when those kids were done school.

Later she comments:

> I feel fortunate because I was a professional, like I don't know that a mom who wasn't a professional could have received that. I think, like I was never sure that what I was doing was right, but I am a fairly confident person myself and I certainly was trying.

Inga recalls being devalued at the Child Development Centre.

> Every experience I have had with a psychologist from the Child Development Clinic has been pretty rotten. A lot of the kids problems they see as environmental, they point the finger at the parent or the foster parent. There is some kind of a stigma attached to being a foster parent and um, so we have been beat up pretty bad by them in terms of them questioning our parenting skills.

Five foster/adoptive parents were also misunderstood and excluded from family gatherings and social events. Connie found her family supportive but friends not so much so. "When we were going to have outings or things like that they didn't appreciate it if we were going to take our daughter, they just wanted our biological daughter." Darlene says, "...the majority on both sides have said, just let her go, I mean can't you 'unadopt' her or something, she doesn't want to be part of your family. Just send her back where she came from." Inga says,

> No, my family, my parents, and my siblings and my husband's siblings as well, think that we are absolutely crazy, just absolutely crazy to voluntarily parent these kinds of kids. We must be insane. ... It's very lonely, when it comes to family gatherings and so on because we are not welcome.

Paula, when asked about whether her and her husband's families were supportive she says, "Not really". ... Even Mom was like that. But towards the end... my mom changed towards the end".

There is also self-doubt, inner examination and evaluation. Edna remembers going to her first workshop on Fetal Alcohol Syndrome and feeling a huge sense of relief. "I had been wondering if it was all my fault". Many others felt similarly. Some expressed it in the form of regrets. Angie says, "I realise now that I should have done some things differently". Edna says, "I would have done a lot of things differently. I look back and my beginning with those kids was all wrong". Fran says, "I was not a very good spokesperson for these children, so that's what I would have done differently."

The re-evaluation can continue on over a span of many years. Hanna still wonders, after seventeen years, if her home was the best possible placement for her daughter:

> I think she needed to be in a home where there were younger children and not other kids who were abusive. ... I mean we struggled through it, but there probably would have been in some ways, a better placement for her. Well, maybe there wasn't. I mean maybe that was the case. It worked out well in the end.

Linda sadly says,

> I wish I had, well, if I had known earlier, a lot of things still upset me. Like when I lost patience with him when he didn't remember, and now you could just cut your tongue out for, and because you just didn't understand and you know, I just wish I had had more understanding when he was really little.

There was also self-sacrifice and embarrassment to cope with. Two caregivers explained that they had had marriage difficulties as a result of differences in parenting strategies. One couple separated for a while and upon reuniting are still struggling to work out their relationship. The other couple must continually work to support and communicate parenting strategies. One adoptive mom has been diagnosed with Post-Traumatic Stress Disorder as a result of the strain of trying to find ways to parent effectively and find services to support her daughter. Three parents talked about having had professionals tell them that they were/are depressed as a result of the build up of the worry and stress.

Most sacrificed in the area of socializing, either because the children were not wanted at gatherings or because ongoing supervision was such an issue and finding responsible babysitters was very difficult. One family says that they have denied their biological children brand named clothes and one biological daughter her driver's license because brand name clothes are stolen and too high demands (from the adolescents with FAS/E) are placed on anyone with a driver's license. One foster parent keeps her daughters in her bedroom because of fear of sexual abuse by the boys with FAS/FAE in her home. One sexually inappropriate incident has already occurred and she doesn't want it to happen again.

Hanna remembers the embarrassment when her daughter took off on her bike down the highway. They were frantically looking for her when finally they got a call. "She got tired and had gone into somebody's house on the road and told them that she didn't have anything to eat so she had come looking for food. I was embarrassed and had to explain." Linda remembers her son pulling up her neighbours' flowers and bringing them home to her as a gift with a very angry neighbour following closely along behind.

These seemingly little embarrassments multiply and increase as the children grow older. When society has no understanding of what the disability is all about and are constantly comparing this behaviour with 'normal' behaviour the differences are most often interpreted as being the parents fault and blaming occurs. This stress and misunderstanding can lead to some very serious medical, mental and relationship complications.

Self-Care and Coping Strategies

Introduction

For most of these caregivers it has been a real battle to raise their children. Knowledge was unavailable, gaining access to services was a struggle, systems tended to blame the home environment and personal sacrifice was a given. However, not one of these caregivers felt that they would make a different choice given the chance to start all over again with the information they have today. So what kept them going?

The Children Themselves

One of the biggest reasons appears to be the children themselves. What I found in the caregivers was a remarkable commitment to these children, a solid strength of character and an ability to maintain a positive outlook. No matter what has happened they continue to advocate with the hope that their children's dreams and the dreams they hold for their children may someday come true. Even those who have lost children through suicide felt a desire to continue to speak out, to advocate and to participate in studies such as this one.

Although affected by prenatal exposure to alcohol, these caregivers saw the beauty, courage and uniqueness in their children. These attributes gave them the energy and determination to keep on searching for answers, to keep on trying new methods, to keep on loving and caring for these children. If anyone doubts this they only need to read the litany of strengths that the caregivers used to describe their children. These covered a wide variety of skills including sportsmen and sportswomen, artists, violinists, designers, builders, singers, storytellers, computer wizards, chess players, animal lovers, seamstresses, musicians, crafters, and bicycle repairers. Personal attributes included caring, thoughtful, loveable, enthusiastic, team player, neat, good sense of humour, ambitious, imaginative, happy, forgiving, and personable.

For the most part their dreams for their children were much the same as any parent's dreams. Most wished that their child could be set up in a nice place to live, find a job and be happy. A few wished that marriage and children might be a part of the dream, others felt that was unrealistic.

Family and Extended Family

As stated earlier, four caregivers found that their extended families were not supportive to them. For the others family were very supportive and helped to sustain them by means of respite and taking on special tasks such as speech exercises. Fran says gratefully,

> When my mother was alive she actually took care of him when he was little because I worked… So I had a lot of supports, like my father when he was alive was very very good to the boys. They always wanted to go to Grandpa's. Now, my partner's mom is involved, well she has always been involved with kids.

Several families had natural networks because a number of parents or siblings also fostered. When asked about the family being supportive Olga says, "Oh yeah. They were, most of them were fostering too." Other couples relied heavily on one another. Mable says, "Just my husband and I worked it out." Paula says, "We have basically stuck to ourselves." Angie says, she and her husband work as a team, "It doesn't work otherwise.

Close Friends and Support Groups

Some caregivers have found informal support networks. Gail says that she "met some other foster parents…. We meet once a month and sometimes there are more and sometimes less people who come…. You can talk about issues that you are dealing with. And sometimes it is just to get something off your chest." Karen says that she was helped greatly by "really good female friends who I could talk to and who would listen. It wasn't that they could solve the problems but I could talk to them and tell them how I was feeling and tell them what was going on."

Personal Interests

Edna found that no matter what " I had to take time for myself – so I jumped back into my art and I found ways of making myself work and it was like respite." Angie says that other interests like "going to our cabin" and "winning money" have helped to sustain them.

Some have a strong personal faith in God and prayer. When asked what has kept them going despite fire starting behaviour, lack of family support, inappropriate behaviour, lack of understanding from the school, etc. Paula says,

> Well, the Lord – prayer and faith. That was the number one. Without that, I don't think we would be here. At one point, he (her husband) thought I was going to have a nervous breakdown. You just got to keep praying. I prayed that things would work out.

Access to Services

Introduction

Access to services and resources was at times both difficult and frustrating. On many occasions, caregivers found that there was nowhere to turn when they needed help. Experience with five main service providers was explored in an attempt to understand how these systems impact on the stress of parenting a child with FAS/FAE.

The Medical System

Caregiver's interaction with medical services varied. Half of the respondents stated that they had to either educate the doctors about fetal alcohol or that the doctor had no understanding at all of the disability. Most of this lack of information and knowledge dates back twenty odd years, but a few incidents were mentioned in the recent past. Paula says, "The doctors, themselves, don't have any training in that." Jane says, "The doctor there suggested I go see a neurosurgeon... neurologist, yeah neurologist. And I took her and I asked if this seizure could have anything to do with Fetal Alcohol Syndrome. And he didn't have a clue." Inga says that her son has just recently run into major problems with his drugs.

> Kids with fetal alcohol syndrome, you have to be very cautious about giving them anything that goes through the liver. So we are trying to get doctors to realise that they need to look at that first and then if they can give something comparable that is metabolised in the kidneys, it is a way better. ... A month ago he became ill, terribly ill. We took him to emergency and here we find out that his liver was in terrible shape, triggered from these drugs. So now he has had to come off of all medications so now we have behaviours, all this autistic behaviour to live with.

Gail is concerned now that her son has become an adult. He can no longer access the Children's Hospital and that means a whole new set of doctors. "So now he's seeing the respirology doctor again and he's sending him to cardiology. But beyond that, we have to meet a whole new group of people now who will have to learn about him."

Sometimes it is not the training but the waiting. Linda says, "I used to get so frustrated because every time I tried to get help for him the waiting lists were like ten years long."

Inga says that in the early eighties the only way she could get a diagnosis was to "go to the doctor and say, 'my child has Fetal Alcohol Syndrome'." He wrote it down and then the doctor would say, " 'what makes you think so' and then I would have to educate the doctor and then they would go, oh, yeh, okay."

A few caregivers felt that they were being blamed by medical professionals for lack of weight gain, concern about difficult behaviour or lack of appropriate parenting. Linda remembers, "I would ask the doctor about it and he would just say, oh you are just too worried, you worry too much and you are too protective and you are too…like it was always me, it was never the baby."

Two other caregivers were very pleased with the service they received. Gail says that she had no problem getting an assessment. "I just mentioned it to his paediatrician at the Children's Hospital and he made a referral. And it was just two or three months and we were in to see Dr. Chudley." Karen says,

> And my paediatrician sent me to Child Development at Health Sciences and that was really a lifesaver for me. At the first interview my son just about drove the psychologist nuts in the interview and I thought good, 'YES'. The psychologist validated all that I felt, he said you would have to be a Cretan not to be excited by this child, you know.

Getting a diagnosis was difficult for some of the care providers and much easier for others. Of the eleven children who were medically diagnosed, three care providers felt a great sense of relief. They said that it finally gave them some answers as to why they were struggling so much with the behaviours and the memory problems. Angie says, "It was a relief. It is a relief all the time to know what is wrong and then you can move on and deal with it". Fran said, ''…there was some sense of relief when you finally got the diagnosis even though it didn't help you figure out exactly how to help him but at least to know that it was, there was a reason".

For others it was more of a confirmation. After a lot of reading and research they had often felt certain that their children had been affected by prenatal exposure to alcohol and finally what they had believed all along was confirmed.

A couple of caregivers felt a real sense of hopelessness when they had the diagnosis officially confirmed, even though it was a relief to have some answers. Darlene says,

> At the time I felt really discouraged, I felt really discouraged because I remember thinking that I wanted an answer for what was going on because it all seemed like craziness. But somehow I felt really sad because in my mind I knew that FAS and FAE were not really all that different but when he said the full-blown syndrome, just the way he said it I just felt a real sense of hopelessness.

Inga reminisces,

> I think I had a real tender spot in my heart for her. I had grown up in a community where fetal alcohol syndrome was rampant although no one had ever identified it. I always remember as a kid myself seeing these other youngsters that were having so much difficulty in school and having a hard time with cause and effect and so on and just feeling really drawn towards these kids. So it wasn't a big, it wasn't overwhelming or anything when I realised that was her challenge as well.

For the caregivers that knew FAS/FAE was a disability for the children coming into their homes, prior to their arrival, they felt better prepared to care for the children. Even though the behaviours were just as challenging, or the systems were just as difficult to access for help, at least they knew what they were dealing with from the beginning. They had the opportunity to make a choice about the placement and had the opportunity to learn from others about how to parent differently. Connie says that she took over fostering her daughter from her mother and knew that she had been diagnosed with FAS.

She says, "I had known her for a long time so I wasn't very surprised by the experiences we had".

The Educational System

School was the next major system that parents came in contact with. In this research study, it was without a doubt, the system that frustrated them the most. Every caregiver identified that their child(ren) had memory problems, that there was an inability to retain information. This memory difficulty was the biggest factor in their children being labelled stubborn, manipulative and disruptive. The only children who had a good experience with the school system were those who were visibly disabled or who were severely behaviourally damaged. There were five children that fit into this category and they all reported mostly positive experiences. Connie said that they even tried to deal with the fetal alcohol challenge with the use of "heavy lead blankets to try to help her relax".

Inga comments, "I think kids that lack facial stigma have a much harder time because it is a totally invisible disability and there is also a mind set out there, almost entirely across the board that FAE is a lesser diagnosis, and it is not, it is not." Debbie comments that her son "is much more easily accepted because he looks different". Her other children "look like they are normal but act different. People don't understand and expect different things from them. So they think they are just rotten kids and bad foster kids."

A couple of the other caregivers of the visibly challenged children felt that their child was either not challenged enough or that resources could have been better spent. Hanna says,

> They had integrated classrooms where these kids spent some time in their own classroom and they went to classes with the high school students. Which in my view doesn't make a lot of sense because, number one, the students, the older ones, picked on a lot of these kids. My daughter ended up having an assistant with her the whole time she was at school – went to classes with her, one-on-one, so that this couldn't happen. But they had my daughter attending a Grade 12-science class.... She'd even have to supposedly write the exam and I talked to her assistant one time and her assistant said it was the most bizarre thing she had ever hear of. The assistant said, 'I write the exam – she doesn't – so she does as well on the exam as I understand the material.' ...

For the remainder of the children in this research study, school was generally a difficult, difficult journey. Four of the remaining children repeated kindergarten two to three times, two of these children because they wouldn't talk to the teacher.

Six caregivers said that their children were labelled as behaviour problems mostly because they could not retain information. Their children ended up acting out to compensate. Fran recalls, "...so because of his learning disabilities he was labelled as a behavioural problem rather than a learning disability, it was a behavioural problem so we really had a tough time in school, a very hard time in school. ... And the kid was constantly thrown out of school, constantly. Betty puts it this way,

> I think through the years these kids are labelled as bad kids, and they are fetal alcohol of some shape or form. They are just labelled as bad and behavioural problems but they are acting out because they don't understand and they can't learn. So they get pushed to the back of the class or are stuck at the front of the class and are ridiculed by the teachers and then that makes them feel worse and then they do act dumb.

Many parents found that the teachers tried hard to work with their kids but they just didn't know what to do with the specific learning difficulties. Darlene remembers, "There was a resource teacher that pulled her out for one-to-one. I think she really cared about her, but she had no idea what to do. She just kept saying, why does she know it yesterday and today she doesn't." Karen remembers a teacher who really tried to be creative. "...He had a philosophy that to control the kids and contain their energy and himself too, he, at nine o'clock, they would jog around the school yard. Things like that." Then, Karen recalls, there were others that did not "...believe in learning disabilities, there is no such thing and you'd get the star chart up". This is after she had paid for a private assessment to find out what her child's learning needs were.

Others described the difficulties they had with schools as not being flexible enough. Inga states,

> She was starting to loose ground but she really excelled at sports, and I think that kind of gave her life. And then, in that particular school, if you didn't do well academically you were pulled off all of the teams and that's what they did and that was just a spiralling down for her. We just couldn't seem to get them to understand that we needed to build on her strengths and one of her strengths was sports. That was really really bad, and see socially she fit in with the teams, she was one of their top players so she was accepted and once she wasn't on the team everyone just forgot that she existed.

Another parent, Angie, speaks to the lack of flexibility. She says that a child "can't get a school aid unless the child is in therapy." Darlene recalls how one teacher in grade seven found something out about her daughter but wouldn't change her teaching practice. The teacher said,

> If I give her the math paper to correct she doesn't get any more correct, you can see where she has erased and tried but she just has different ones wrong. However, if I giver her a clean sheet and the old one back and tell her to do the ones she didn't get right, she'll do them and maybe get 13 more right. And I said, oh, I'm really excited… …She said, we can't do that, they have to correct on the sheet that, you know, and I said but why?

A few parents were able to advocate strongly enough that some of the needs of their children were met.

> Several of us parents … went to … and asked if they would set up a program for the kids that were coming there. …And they did. It had nothing to do with Fetal Alcohol Syndrome. The other two children had Downs Syndrome but nevertheless they did do a little bit of extra. They provided an aid for the children. … Eventually, from grades nine to twelve she did a lot of work experience.

Linda says that she did "run into a couple of teachers that actually found creative methods. Instead of having him counting flowers or oranges and apples they found that if they had him counting trucks or cars or planes, anything with wheels that he did much better. … But very few teachers would even go to that…"

Angie says that one of her fetal alcohol children has an amazing support network the other has nothing.

> We have had teams working with him, teams of teachers and student teacher's assistants. He has had all this stuff and its been helpful and that's what I find, that, - and the next child has nothing, absolutely nothing, and because he has acted out and done just about any old thing they've given him this aid. And yet he has the same thing wrong with him as the next child who gets nothing and just falls through the cracks and its just because you are out with your behaviour.

Other schools tried hard to meet the needs of the children but it was difficult. Nancy says, "They did the best they can, you know, in modifying the program."

Unfortunately, many caregivers found that the schools didn't know how to deal with the disability. As a result self-esteem was shattered.

This phrase, "self-esteem was destroyed/shattered" came out over and over again. School was such a struggle for most of these kids and they were so misunderstood, that most left, even those that graduated, with low self-esteem. Jane says, "He would put her in the midst of four haywire boys to keep them quiet and of course she would learn nothing. Like it was a battle and of course then by the time she hit high school she was so sick of being a resource kid she said I just hate being a resource kid and quit. Her self-esteem was shot." Edna believes that, "it has to be a constant teaching process and then I think there would be successes because they have had more successes. Self-esteem is so important". Linda says painfully,

> They had this horrible thing, in grades one, two and three. You would go in and they would have this list up on the wall with the little stars and his name was always on the bottom. I used to think how demoralising that would have to be year after year, class after class, you are always at the bottom and even in art and he was a wonderful artist, he never got an A, he failed a lot of times. ... It was things like that because he wouldn't draw what they wanted him to draw they would fail him.

As a result, many of the children, as they reached the teenage years, found that school was too difficult, frustrating or unfriendly to continue. The streets, alcohol, drugs or abusive partners were often where they found comfort.

Dr. Streissguth's research on secondary disabilities corroborates that disrupted school experience is very high for teenagers with FAS/E. "Disrupted School Experience (DSE), defined as having been suspended or expelled from school or having dropped out of school, was experienced by 60% of patients (12 or over) (1997, p. 34).

The Legal System

Seven of the caregivers had not parented children with FAS/FAE who had involvement with the legal system. It is very interesting to note that for all but one of these seven caregivers, the children who had not been involved with the law were the most severely damaged children in the study. That is, the ones who had been diagnosed as full-blown FAS. Two of these seven caregivers also had less damaged children in their homes, they were also free from involvement with the law.

The remaining nine caregivers had at least one child with FAS/FAE in their home involved with the legal system. This involvement included, erratic behaviour, shop-lifting, assault, underage drinking, mischief, theft, break and enter, buying alcohol for underage kids, possession of drugs, drunk in a public place and rape. The consequences for these behaviours included such outcomes as having the charges dropped or dismissed, being banned from a shopping centre, probation and incarceration.

A couple of the foster/adoptive parents found judges to be somewhat flexible and understanding. Darlene recalls: “I think that the judge knew a little bit about FAS/E and ended up dropping the charges.” She remembers him saying,

> This is a discharge, a complete discharge, it’s like you’ve never been charged with this. The only reason I’m doing it is like you said, I’ve looked at your record and you have FAS/E and if you have managed to only have a couple instances with the law, you just keep on doing what you are doing. You just try your best and I don’t want to see you in here again.

Inga says:

> She did go before a judge on some charges and I went with her and spoke to the judge ahead of time. I felt that the judge was very compassionate,

> very fair and laid out the expectations very very clearly and that that was good. But, had I not gone, I think that she would not have been treated fairly. And that's kind of the way it has always been, you know, I feel like I have always gone ahead and cleared the path for her first.

One adoptive mom, Karen, had many questions and concerns about the legal system. Her son was incarcerated a number of times and eventually committed suicide while in prison. She relates that a lawyer abused her son,

> I didn't know what I was going to do. He had this lawyer whom on this court date he and the lawyer didn't show up and there was a Canada wide warrant, he was a homosexual and had taken my son to the gay bar. I began to think is everything sick?

She says that it didn't stop there. Other inmates abused him as well. She felt that the guards didn't seem to recognize what they are dealing with.

> And in the jails and in prisons, they really need to recognize what they are dealing with. And there is literature and they don't access it. I was granted standing at my son's inquest to look at recommendations. And the prisons, they use uneducated people, they don't educate, they, there is nothing. They are not even reading literature, there's not even, I mean there is published prison literature, but it is not anywhere where the damn guards can read it… I mean my son died, I mean he might have died at another time, but the prison was putting in a computer system and his direct, the person who was in charge of him, was in charge of that computer program. He had no time to listen to me to do for my son what needed to be done and he passed the responsibility on to a guard and the guard won't accept it because of the union difference.

The Child Welfare System

There were a number of concerns and suggestions raised about the effectiveness of the child welfare system in assisting and providing ongoing support to those who had either adopted or fostered children with fetal alcohol related issues. All of the adoptive parents in this study went back to Child and Family Services to try to either gather more background information about their children or to ask for some support with the challenging behaviours they were trying to understand. Angie says, "you couldn't go to CFS unless you wanted to give your child back and we weren't doing that, we had no thought of that".

Darlene kept calling CFS and they would say, "Well it sounds like you are doing everything that you can do." She kept pushing and talked to an Area Director. He sent someone out to talk to her family. This person told them that if they "insisted, her daughter could be put in a foster home." Darlene said, "I am not asking you, I am not saying I want my problem to disappear, I am saying we need help as a family and I do not want her help to be outside the family." It finally reached a point where her child went to a closed setting but this was not helpful either. When Darlene started to ask if there might be a chance she had been affected by prenatal exposure to alcohol the response was, "Until you stop looking for excuses for her there is not going to be any improvement. I just felt like the worst parent". Inga's experience was similar,

> It was just awful. We went to Child and Family because our adoption contract said that if there was an adoption breakdown we had to notify the agency. So we went to Child and Family and said well this is definitely an adoption breakdown, she is no longer living in our home and yet she is a minor, we need help. We need to get her into a drug and alcohol treatment program and so on. And they flatly refused, they said, you have never had involvement with this child with this Agency and at seventeen we are not about to help you… we were devastated.

Many other adoptive parents went back for information to find that there was little that could help them understand what was causing so much difficulty for their children. Karen recalls,

> I don't think that I really started knowing any of his background until he was about six years of age when I started questioning Child and Family. They didn't tell me that the family were alcoholics at that point either; they just said that he was from a large family. Actually I think they told me he was from a family of four when he was from a family of nine and that one of his brothers had had cancer but survived.... That is all that they told me.

Linda did have her child placed in foster care because she could not manage both his behaviour and keep her other children safe. She felt that Child and Family Services did well at placing him in a couple of foster homes that really cared about him and did their best to support and manage him as well as keep her informed about how he was doing.

There were a lot of mixed feelings for the rest of the care providers. Some felt that the payment and respite plan were very fair. Others felt that they had to pay a lot out of their own pocket so that the children got a chance to participate in the same kinds of activities as their other biological/adoptive children. Many felt that it was unfair that they had to find their own respite workers because they needed skilled and capable people that they did not readily know how to access.

Gail stated, "I found out that other people get regular respite. So it's not something that social workers say to you, 'This is available'. You learn that more from other people." Olga feels the same way " I know other foster parents who have time off and with me it is oh you are such a strong person you don't need it. ...I may be a strong person but I still need a break." Some foster parents felt that they sometimes had very knowledgeable supportive workers and others felt that they did not understand FAS/E and were at times blaming and became stumbling blocks to getting appropriate assessments or services. Inga says,

> You know, it depends on who the worker is. Some workers are just fantastic and you know some of them actually know a whole lot about Fetal Alcohol Syndrome, some don't know but are willing to hear what you have to say and then there are others who couldn't care a less.

Most participants in the interviews really wanted to see mandatory education for workers, more training, support and ongoing education for foster parents and adequate information being shared with foster parents before children were placed. They also wanted to be treated more as team players, getting recognition that they were 'experts' in terms of understanding what it is like to live with a fetal alcohol child and what possible strategies might be helpful. Baukje Miedema (1999) writes about this paradox,

> Even though foster mothers care for the foster children "around the clock," it is the experts, the social workers who are entrusted with the long-term planning for the child. This is a rather incoherent arrangement at best and precarious at worst for the foster child (p. 78).

Adult Services

When asked about adult services, Inga responded,

> I don't think the services are available to them. I think that the funding is very limited. I think that a lot of these kids end up on welfare and committing suicide. I think a lot of them do. I mean, just in my circle of people that I know, I can think of five kids, right off the bat with FAS who have committed suicide.

Research from this study reveals that for the five most severely damaged individuals, Community Living is either in place or applications have been made and it is fairly certain they will be accepted. Two other young adults with FAS/E have married and between supportive families and spouses are managing quite well. Two young men have committed suicide. Another young man is holding down a steady minimum wage job and is living on his own. The remaining individuals with FAS/E are not qualified to receive assistance from Community Living or any other Adult Service except Social Assistance. These individuals appear to have 'fallen through the cracks'. They are struggling with alcoholism, abusive relationships, loneliness, and unemployment. It is in the mildly mentally challenged range, or the borderline range, where a great number of children with FAS/FAE fall, that adolescents and adults find a shortage of services and resources. Persons in these ranges are not considered eligible for adult services because they are perceived as being slightly too high functioning for the programs. Absent a full assessment and flexibility in the admission criteria, many of these young adults are left to fend for themselves.

Fran asks, "What happens to this kid when he turns 18? He is lost to the system and because of his alcohol abuse I am really afraid for him because people are really going to take advantage of him." Jane speaks to her frustration of trying to help her daughter find a spot where she can be supported through adult programming. She gets her telephone directory and reads off fourteen different connections she has attempted to make to find service for her daughter. These include everything from the Women's Resource Centre to Skills Unlimited to Society for Manitobans with Disabilities. Her frustration is summed up in these words. “She never fit in anywhere. … Everyone has very specific sort of things like, … Scope is another one. At Scope you have to be on anti-depressants.”

Many find housing to be a major issue when their children try to move out on their own. Olga says, “And when they do move out on their own, like I’ve known places where they have found placements for the kids but I wouldn’t even have my dogs stay there, they are just really horrible.” Jane struggles,

> I don’t know, in some ways, whether it’s good to place so many people who are depressed or who are on welfare together. It’s more depressing for the people who live there. However, it’s better than living in one little room some place in a rooming house.

Employment is another major issue for these individuals once they become adults. Most of the young people have not found the work place to be a very tolerant understanding environment. As stated above one young man has a steady job. Two other more severely affected boys in the Community Living program, have jobs through WASO (Work and Social Opportunities). Another of the more severely effected persons worked for ARC Industries for a number of years. One young woman holds down casual seasonal jobs harvesting crops or working in a small convenience store at the lake. Another young woman does occasional jobs such as participating in Hilltop Research experiments. Most of the others have been fired for being too slow, for dropping things, for absenteeism, for being late or for alcoholism.

The caregivers generally felt that work was extremely important for these young people. Most of them, however, would need tremendous supervision and a lot of patience and understanding from their employers. Some would need repetitious work so it could be learned and remembered. Others would need some flexibility because of their struggles with focusing. Betty recalls her son's experience,

> The new manager fired my son so now he has no job. He feels really bad about it. The old manager said he was doing a good job, but she knew what speed he went at and what he was like. This is the part that worries me, these kids are going to grow up and they are never going to be able to hold a job because society doesn't understand the needs of these children. There is nothing out there, there is nothing out there for them at all and its scary because there are so many of these kids.

Jane has a similar story. Her daughter worked cleaning at a hotel for three weeks and then came home upset one night because she had been fired.

> I asked what was the matter. She said, "Well, she told me what to do and she told me I couldn't leave my cart. But she went to work on a different floor and then I didn't know what to do, and I couldn't go and ask her because I couldn't leave my cart. An ordinary person would have figured this out. But she was totally stymied. ...

Strategies for Intervention

Introduction

This section considers some of the strategies put forward by the women interviewed and compares these findings with those in the survey carried out by the Youth Secretariat. There are also some helpful comparisons with Baukje Miedema's work (1999) in which she interviewed twenty foster mothers.

Many foster and adoptive parents had strong feelings and opinions about what needs to be done differently and how it needs to be done differently. They felt that changes needed to happen in order to enable them to take better care of themselves, make their job easier and to assist them in bringing up more whole, healthy and productive/successful societal members.

Medical

Some of the factors identified in improving medical services for adolescents and adults with FAS/FAE included early diagnosis and assessment services. Foster/adoptive parents wanted to have easier and more thorough access and assistance from psychiatric and psychological services. The same theme of education was raised again. Not just that doctors and psychiatrists need to have a good knowledge of fetal alcohol and its effects but that nurses, hospital social workers and family therapists all need to have a good solid base of understanding. Foster/adoptive parents do not benefit from being blamed for the challenges that their children's behaviour is presenting. They need support and assistance in the form of new strategies and practical suggestions.

Karen sees a need for more research. "Yes, more physiological and biological research has to be done, I mean we are just beginning to cut into that, you know mood swings, if we are depressed, if we are stressed..."

Education

The greatest need that these caregivers identified was for more education around FAS/FAE issues. The need for more education encompassed all professions and indeed all of society. It was expressed by many of these women as something they felt should be mandatory for everyone involved with these children. Educators, nurses, doctors, social workers, judges, lawyers, police, and business people were just some of the people specifically named who needed ongoing and updated education. Nancy says,

> I think with FAS and FAE, I think there needs to be a larger piece, there has to be something that is available that goes through the educational system for people who are going to become teachers. There needs to be something, I took a course on it and that is mandatory. It doesn't matter what profession one is in, because it is something, you know, whether you are in Child Welfare, you are a teacher, whether you are a nurse, a doctor, a police officer, it is a big piece and certainly within our Aboriginal Community.

Gail agrees that there needs to be more education. "I think people need more knowledge. And I think some of the information is getting out. But we still run into people who think that kids will grow out of it." Paula says, "I think everybody should be educated – all the social workers, all the teachers, principals. Even RCMP should be educated. Because they (the kids) tend to get in trouble with the law."

Education was strongly stressed because these caregivers felt that caring and supporting people affected by prenatal exposure to alcohol is a co-ordinated community effort. If one part of the jigsaw puzzle does not fit, the ramifications can be quite devastating because of the inability of many people with FAS/FAE to generalise and reason. Concrete thinking, impulsivity, lack of anger management all makes them very vulnerable to victimisation and depression. Many with this disability need to have the same rules and structures put in place whether they are at home, at school, or in the community. Therefore it is so very important to have all the people who are impacting upon the individual's life educated about the disability and implementing the same structure and strategies. It is also extremely important that their self-esteem needs to be protected. This can only happen if people understand the disability and don't continue to blame or place expectations on these individuals that are unrealistic. Hanna felt that whether at home, in school, or in the community, caregivers and professionals involved with individuals with FAS/FAE need to insure that they are not punishing these persons for things they do not understand.

> If they don't understand then certainly there should be no consequences, and if its behaviour or acting out, then there needs to be a consequence. It has to be connected for them. They have to know that the consequence is because of the particular behaviour and they have to be able to understand that.

The summary put out by The Children and Youth Secretariat and the Coalition on Alcohol and Pregnancy (see Appendix 4, p. 240) adds validity to these findings.

> Overall, about 29 percent of survey respondents reported that they had not received any formal training in relation to FAS/FAE. Lack of formal training was reported by 31 percent of workers in the social/human service/health care and justice systems and by 29 percent of workers in the education/day-care systems. By way of comparison, 19 percent of parents or caregivers reported that they had not received formal FAS/FAE training.

Educating young teens/adults with FAS/FAE is certainly another educational piece. There will be barriers to whether women affected by FAS/FAE are able to manage their addictions during pregnancy. Some of this depends on their ability to comprehend the correlation between drinking and the disability. For others it is a question of their economic situation. Most individuals with FAS/FAE are faced with poverty as they cannot find work and therefore rely on welfare. This sense of hopelessness as well as any prior or present abuse can often lead to addictions that numb the pain.

Connie says,

> I just feel that prevention would have been the best thing, it's the most important thing and it isn't happening. With all the education that's the most frustrating thing to me, people have not just one child with fetal alcohol syndrome but up to eleven. It makes me really angry because nothing happens to these people, these parents, you know. You'd think they would teach them, show them what they have done to these kids and educate them about the damage that they are causing and the cost and all the work that has to go into one child because of this and it just keeps on going.

Other parents like Angie have given their children the information but sometimes are not sure whether it is understood. Angie says,

> I'm in the role of teaching her not to drink. I don't think she drank too much with her little girl, it doesn't show that she did. So many people ask, can you give your kid fetal alcohol? Her husband still says, 'see it didn't hurt her'. I don't think you can give some people knowledge. ... I can't educate her, its just not getting through. I've tried and tried.

Other foster/adoptive parents gave this information to their children and it made a big difference. Inga speaks with great pride about her daughter who was out on the street living a very 'free' lifestyle but when becoming pregnant pulled herself back to a place where she was taking great care to eat properly, not drink and ensure that she gave birth to a healthy child.

Apart from the need for more education, there were several other areas that these women identified as needing to be changed.

The Education System

There was a general feeling by many foster/adoptive parents that the school system is not meeting the needs of this population especially in the junior and senior high years. Most children by this age were no longer able to keep up with the academic requirements but needed specialised resources to reinforce basic academic and social skills and specialised employment skills. Help was needed not just for those who were displaying behaviours that were disruptive but also to the quiet ones who were struggling as well. Others who did have more academic ability often needed more one on one teaching methods that allowed for individualised learning either at a slower pace, through use of much repetition or alternative testing methods.

Some felt that their children would have benefited from segregated classrooms or at least more structured, and smaller classrooms. Others felt that there should be school for these children all year round because they lose so much during the summer holidays. Overall, there needed to be more flexibility, creativity in teaching methods and specialised education and training for the teaching staff.

The summary put out by the Children and Youth Secretariat noted that the "parents of older children strongly identified supports needed for supported (community) living, educational and employment programs for their children" (see Appendix 4, p. 210). I am not clear whether "educational and employment programs" includes such things as teacher aide support in school and/or alternative programming for teenagers. It certainly was a concern to the care providers interviewed in this study.

In order for many of the above strategies to be implemented there would need to be more special needs funding given to the schools. It was generally felt, however, that the government "doesn't want to do anything, it just costs too much" (Angie's words). Fran says,

> I think the Government is scared to hear how the young adults are doing because of the money that may need to be put out. And they should be scared because you know what, pay now or pay later because you know what, they are going to have to pay it some time later, because I know that the statistics show that a lot of these FAS adults end up incarcerated.

The women interviewed stressed that a much greater emphasis needed to be placed on searching out and focusing on these children's strengths rather than trying to squeeze and force them into the existing mould for academic prowess. At all cost their self-esteem needs to be protected.

One caregiver, Betty, managed to get her child into a program that only emphasised Math and English, the rest of the subjects were to do with her specific strengths and interests. Betty says, "We put her in a program where they don't take the extra curriculum, they just take math, English and social skills and just concentrate on those and so she went there..."

For many others social skills training was really needed but could not be found. Gail says,

> Social skills for her is the saddest part of her day. She hates recess... she doesn't have friends. Kids don't want to play with her. It's not like she beats them up or she does dumb things. She kind of stares at people sometimes. But she is never a behaviour problem kid. Trying to get their help when you don't get extra funding is very frustrating.

Another mom, Mabel, says that her son got through school but he had no social skills, which got him in with the wrong crowd. His life has just spiralled downward ever since. "...He learned very, very slowly and he was almost a silent trouble maker. He did know how to make trouble but he got away with it quite often and got other kids in trouble too."

Many parents expressed the need for their child's learning difficulties to be identified from the beginning so that individualised school programming could be implemented for them. They also want to be a part of the planning. Several said that a separate school system right from kindergarten to college was necessary. One caregiver, Karen, felt that because "their rate of maturation is slower", there needs to be a different educational system put in place for them.

> ...Perhaps a community college setting or something like that where there are studies and they don't need examinations because people can learn, they can do work that other people do that pass exams but they can't pass exams or it's too stressful for them, they have to be examined.

Argyll was a lifesaver for her teen daughter who had pretty well given up on school and the school system had given up on her. Argyll was "very small, they had about 20 – 28 students. ...These kids had been kicked out of every major high school. So this is the last stop. ...It's all about treating them with respect."

> Inga used a private school that offered smaller classrooms and private tutoring to assist her daughter. This made a big difference for her daughter. She was able to keep up with the required academics.

Edna really felt that we should look at a different approach to schooling these children. She feels that school is

> not just an eight-hour thing, they don't take summers off, they just keep on learning, and they drum it into their heads and I think that is how they have to learn. If you take a summer off, those kids have forgotten everything when it starts and it is not fair. They really shouldn't be in the school system. It is not built for them; all it does is kill their self-esteem. It's just terrible.

Computers were mentioned as a real asset to these kids. Karen says, "Fetal alcohol kids learn really well with computers. Computers don't miss any steps, they are not threatening, they don't give you heck, they don't reprimand you, they reward you, they are very logical and they are focused. She also speaks about how open area school classrooms are disasters for these children.

> Kindergarten was marvellous because he had a teacher who was very structured. … And he would have his whole day organized… And this was a closed room and he did exceedingly well in Kindergarten. He hit grade one, in an open area, and his teacher believed in teaching with headphones and tapes. Well he nearly went crazy that year. Grade three and on, it was still open area schools and it was just disastrous.

Legal

The most common theme stated by foster/adoptive parents who had their children in the prison system was that our present system did not work for them. Prison is the wrong place for these adolescents/adults. It was not a question of whether they needed to be held accountable but that there needed to be different sentencing and alternative placements. The focus needed to be changed to building social skills, developing skills for employment opportunities and addiction treatment.

Karen says, "The justice system from what I know is aware that fetal alcohol people do not belong with other criminals but they don't have another alternative." When her son was very suicidal she "fought with psychiatry but they wouldn't admit him again." His probation officer said that he had to go to prison because "if psychiatry wouldn't keep him, keep him safe, he was a danger to himself. It was horrible." She says, "they should not be housed with mainstream criminals. They need, they can behave with structure, they need a more structured place, they still need meaningful work."

Nancy remembers being called by a person from her home community who expressed concern because her son "didn't know what he was in for. He didn't understand what was even happening to him." She strongly feels that prison was not the place for him. "Rather than the lock up institution…. They need to find ways to assist in helping them have the opportunity to kind of refocus their lives, so that they can manage later."

Paula says, "I think the legal system has to understand why some of these kids are like this… even though they may get into wrong, they can't just ignore it, but there has to be a way – like making them do other things rather than incarcerate them."

The Children and Youth Secretariat summary did not comment on this area of concern.

Child Welfare

Many foster/adoptive parents felt that they wanted and needed to be provided with more basic knowledge and understanding of what Fetal Alcohol Syndrome/Effects is and how to manage the behaviours before children with this disability are placed with them. Edna says, "…they should at least for one thing let us foster parents know what we are getting into."

Darlene felt that there needs to be a lot more discussion at orientation about the importance of culture when placing children. "…They did talk about Aboriginal children and they just kind of said it was important to give them some culture and they just sort of covered that point so quickly."

Along with being provided with more information, it was felt that children need to be assessed prior to placement whenever possible. Nancy says, "One of the things that I think needs to happen almost immediately is an assessment. ... We need to understand what this child needs." Some of the tools required were such things as an understanding about how to ready them for school. They wanted more knowledge about their child's needs so they could advocate for better and more appropriate school placements.

Once children with FAS/FAE are placed in their homes, they wanted ongoing support and training. The need for a number of different supports was expressed. Women wanted to have support workers from the agency who would not prejudge them and quickly remove children from their homes if they were having a difficult time with the behaviour. They wanted more frequent support that wasn't precipitated by a crisis but sometimes just a check in to see if all was going well. Adoptive parents wanted to have ongoing support and access to services if they were having children with FAS/FAE placed with them. Foster/adoptive parents wanted more training through workshops (paid for by the agency if possible), more relevant up-to-date reading material and ongoing active foster parent support groups where they could learn from one another and other experts in the field.

Another frequent request was for the agency to support them by providing respite on a regular ongoing basis with consistent skilled respite workers. This respite needs to be found and provided for by the agency, as it is almost impossible for many foster parents to find people in their informal social network to do this job for them. This method of self-care was expressed as very important to them. Betty says,

> ...The agency tells you to find your own respite worker. And now we just got new letters out in March saying that you can't have anybody in your house even to baby-sit your kids unless they are passed by the agency and all this stuff and again its really difficult.

Gail feels that the agency needs to have a lot more organized respite.

> But so often respite is you finding someone who will look after your kids, not all at the same time or... So if there was something organized. This is a good place – people trained to work with these children or young people. I think that would be excellent.

Miedema (1999) found that the foster parents she had interviewed were raising the same concerns.

> If a crisis arises the foster mother will have to deal with it herself without the support of the social worker, adding to her already very demanding schedule of day-to-day care of foster children. In addition, many foster mothers felt that social workers often did not inform them about additional support services such as relief care, baby-sitting services, day-care fee reimbursement etc. Many foster mothers stated that they had to aggressively pursue these issues in order to get informed about the support services to which they were entitled (p. 77).

Another suggestion centred again on the issue of caring for adolescents with FAS/FAE in a more community-based sense. Mable explains that there needs to be more assistance provided for children with FAS/FAE.

> Especially when they go into their teens. There definitely needs to be so much more organized activity and they need more activity with their own kind of people, Aboriginal people. And as foster parents we need assistance with keeping them off of the streets and busy and feeling good about themselves.

Some foster and adoptive parents needed alternative placements for their teens for short periods of time. The worry was that there was no place with people trained to work with their children and they worried that if they were put in with teenagers who were street smart they would quickly pick up on other behaviours that would put them more at risk.

Paula says they placed their son for a short period of time to help him understand that there were rules at their house. It also gave them a break and helped the rest of the children in the home settle. "Just for a period of time, until the boy wanted to come back. Until he realised that he had it good where he was. ... It worked for him. He never ran away any more." Darlene says,

> I think for kids who are really getting into risky behaviours they maybe need a closed environment. I think that if there were staff who really understood about FAS, more specialised and not just all locked together with the other behaviours. She met kids at Marymound that she still chums with that got her into all kinds of stuff that she wasn't into before. So something like that, or just an emergency home, like where I could, like when she was here, she wasn't always drunk but even if she was just drinking. Or if she says can I come home and I said no you can't, if there was just a safe house or something that she could go to...

Adult Services

About half of the persons affected by prenatal exposure to alcohol in this study were struggling as adults either with employment, addictions or independence. Many of their caregivers were supporting them, either emotionally or financially. Several factors appeared to stand in the way of their ability to fit into society in an accepted way. These factors include low self-esteem, substance abuse, and lack of life skills, lack of job skills and an intolerant impatient society.

Inga says, about adults with FAS/FAE, "there could be opportunities for them in the community with some degree of supervision". Many persons affected by fetal alcohol are not ready for independence at age 18. They need ongoing support. Darlene called it "crisis management". There are many times when they get into trouble because they are impulsive, they have difficulty with money management, they are not sure of the time and they don't understand many of the rules of society. Karen says, "...They need a mentor, they need cues. They need to be cued that this is a dangerous situation, this is whatever."

Loneliness is a big part of their reality as well. Darlene felt that a "case manager, ... someone who is on staff all the time" would be extremely helpful. Darlene says it would make her daughter feel safe because sometimes she knows she makes a bad choice, and she says "I need someone to talk to about it, sometimes I wanted to talk to you but like you weren't there so I went and got drunk". She recalls when her daughter actually sat down and wrote a letter to Family Services asking for some help. Her daughter wrote:

> What I really need, like I use to be really good at sports, could you pay for me to go to the Y or could I get some bus tickets or swim tickets, ... could I just go for coffee with someone. They wrote back and said that none of the services that you have listed are available at this time.

Fran looks at her son who is about to turn eighteen and feels strongly that he is going to need that ongoing support well into adult years.

> He will need someone more his own age that can say its okay, you fell but will pick him up and get him going again. Cause if it is us, he'll say see mom, you are bitching again mom. And I'll say no I'm just trying to do this for your own good. ... a roommate that can help him up in case he does fall and somebody that is going to help him with his education. I mean because he can read and he can write but just barely.

Several adoptive/foster parents felt that a supervised apartment set up would be an ideal way to help combat some of the loneliness, aid with the need for supervision around money management and life choices, and assist with the difficulty that exists around finding appropriate housing. Angie says, "it would be nice even if they could be set up in an apartment block where there was somebody who could guide them, check them in and check them out".

The caregivers generally felt that employment was extremely important for these young people. However, most of them would need tremendous supervision and a lot of patience and understanding from their employers. Some would need repetitious work so it could be learned and remembered. Others would need flexibility because of their struggle with focusing. Betty says, "The scary part of it is that these employers don't know anything about FAE so they don't get a chance to do a job." Jane speaks about the difficulties with maintaining employment. "Most of the time, they are not willing to employ them because they work too slowly, they don't get enough done; they need a lot of supervision. Maybe if somehow they could just get their Welfare cheques through a company."

These issues were largely echoed in the results of the Children and Youth Secretariat survey. It found that parents of older children had the most trouble accessing services for "post-secondary education, supported employment and living programs and 24 hour crisis support services." (see Appendix 4, p. 228)

Other foster/adoptive parents felt that there needed to be more flexibility with social services to accommodate the special needs of their children. Some adults with

FAS/E are disabled in a way that makes work almost an impossible task. This could be either because of physical disabilities, or less often acknowledged, because of cognitive or CNS damage. Darlene cannot understand why the money that her daughter was being given through welfare could not go towards a mortgage. This would allow her daughter to live in a small house near Darlene's home. Darlene and her partner could then help support her both on a practical daily basis and financially when the need arose. "When we asked them if we could buy a little house handy to us, ... Like if its $286.00 per month and we could work it out that would be what the mortgage could be. They said no, we can't do that."

Darlene also wonders about finding some way to ensure that persons such as her daughter do not end up going without food. Difficulties with money are a very common struggle for many adults with FAS/FAE. Darlene wonders about having some way of holding back a discretionary amount on their welfare cheque. "...Where she comes and says I need some money for food, maybe not give her a twenty, but maybe three dollars a day, or just, or say here is a voucher, you can go to Salisbury, I don't know, something like that."

Overall, these foster/adoptive parents felt that they needed to be recognized as experts – possessing relevant first hand knowledge about the children in their homes. As such they need to be part of the team in caring for these children at every age level. Inga expressed it this way:

> And I know there are other foster parents, I am not exclusively the one, there are lots of really good ideas out there. I think foster parents who care for these kids and have for years are a good resource for workers, actually.

> Because they are the ones that are in the trenches and they know what works and what doesn't and how to survive.

The Children and Youth Secretariat survey had similar findings; "Case management services (including advocacy services) were identified as needs by parents, with particular emphasis on preferences for joint participation with service providers in decision making" (see Appendix 4, p. 209 - 210).

CHAPTER FIVE

Discussion

Introduction

In the previous chapter the combined voices and ideas of the women interviewed were presented in a descriptive manner. Practical ideas about improvements and changes to the present delivery of service to both their children and to themselves as foster parents were presented. In this chapter, these voices will be analysed from a feminist perspective. The ethic of caring and the phenomena of mothering will be more closely explored in terms of the work these women do. The focus is on the feminist critique of child welfare and the way in which it affects female caregivers and the Aboriginal population in Winnipeg. It will also consider the issue of caring in context of the differing philosophies of caring between mainstream and Aboriginal societies.

Women's Caring

Graham (1983) explores the concept of caring and points out that there are actually two dimensions to caring. The first embraces the emotional aspects of being present for someone else and the second aspect is the actual physical activities involved in sustaining another person (p. 13). In our Western society the care of others has been relegated to women (Guberman, 1990; Forna, 1998; Baines, Evans, and Neysmith, 1991; Abramovitz, 1988 and Graham, 1983). According to Baines, Evans, and Neysmith (1998) this assumption "continues to underpin policies, programs and practice (p. 4).

Western society has historically placed men and women in defined roles, women being defined in terms of their 'caring role' and men being defined in terms of their 'doing role' (Graham, 1983, p. 18). This role division is not only disturbing from a woman's perspective because women are restricted from full participation in the economic and political sphere of society but disturbing from a man's perspective because they are viewed as needing to remove themselves from the nurturing emotional side of caring and relating to others. Neither side have opportunity to reach their full potential. Unfortunately, the struggle for men to regain their "feminine" side is much slower in coming than the struggle for women to become fully visible in all aspects of society. This is no surprise because the role that men play in our society is a role where power and control are visible, valued and rewarded. Women's roles, on the other hand remain invisible, devalued and unrewarded. These roles have been learned and passed on through the years. Many women do not question these roles but judge their value and sense of worth by their own successes at being a devoted, nurturing and perfect mother.

The Women Who Foster and Adopt

Most of the women in this study saw their caring for teenagers and adults with FAS/FAE as an extension of their mothering experiences. They fostered and adopted out of an altruistic need to fulfil their role as nurturers and caregivers and to provide what they recognized as a valuable service to society. Many women were already at home looking after children and felt that they could both make a little extra money and provide a valuable service to a child(ren) in need. Some grew up with foster children and felt they wanted to carry on with a model their mothers had provided. They felt that their mothering experience could be used to help other children.

A few foster/adoptive parents are beginning to view their caring for children with FAS/FAE as specialised work. Inga says, "I have loved my career of parenting FAS kids. I have loved it." But, there are still many others that see caring even for these high needs children as something that is nothing special. Paula said, "Caregiving just comes natural."

Some women found an emptiness in their lives when their children left home. "My son decided that when he turned 12 he was going to go and live with his father which was fine,... I found my life to be very empty.... A girlfriend of mine...suggested that I be a foster parent."

Other women became foster parents because as teachers or nurses they were recruited. Fran says that she was working at a couple of schools in the north end of Winnipeg. "They were recruiting foster parents to try to keep kids in the area." She said yes. Nancy was asked to foster because she was First Nations and there was a need for culturally appropriate homes. Olga's fostering came about through her work experience. She ran a group home for a while and then decided that it would be easier and provide more stability if she fostered from her home. Her parents had also fostered for years.

Often adoption grew out of a sense of wanting to ensure that a particular foster child would have stability. Foster parents had become very attached and did not want to risk ever losing that child. They also felt it was in the best interests of the child to know that they belonged to that family. One woman adopted because she could not bear children of her own.

For most of these women, the desire to care for children appears to have come out of a need to fulfil the role of nurturer that they had accepted as part of their place as women within society.

The Motherhood Myth

The motherhood myth as defined by Forna (1998) is depicted in the image of the perfect mother.

> She must be completely devoted not just to her children, but to her role. She must be the mother who understands her children; she is all-loving and, even more importantly, all giving. She must be capable of enormous sacrifice...She must embody all the qualities traditionally associated with femininity such as nurturing, intimacy and softness. That's how we want her to be. That's how we intend to make her (p. 3).

Many of the women in this study have accepted this ideology of the perfect mother as part of their role as foster and/or adoptive mothers to children, teens and young adults with FAS/E. This was seen in a variety of ways through the voices of these women. One way was the blame and guilt they placed on themselves. Darlene says,

> She just didn't know how to play. I blamed that on myself because I thought, well, a lot of times even when she was playing with other children I was sort of involved in the play and I thought well now she can only play if she is directed.

Paula speaks of going to court with her foster son the first time, "Oh, did I ever have a hard time. I felt like I'm the one that did the wrong. I guess I sort of blamed myself- like, why didn't I do better - that sort of thing." Edna wishes that she had understood the children better when they first came and would not have been so harsh with disciplining them.

> And I use to just not understand why they weren't doing what they were suppose to or how they could possibly forget so I didn't believe that they were forgetting, I thought they were just trying to be jerks or trying to be little brats so they got punished for things they shouldn't have got punished for.

Another way in which women exhibited a desire to live up to the role of the perfect mother can be seen through the way in which they sacrificed career aspirations or job opportunities in order to remain home full-time to look after their children. Prentice and Ferguson (2000), (citing Maynard and White, 1985), point out that the message that comes from "much of the child development literature has traditionally assumed the 'mother at home' model of child care is superior to other settings.... Mothers regularly express feelings of guilt, regret and longing when they are unable to meet expectations" (p. 127). Forna (1998) describes how theories of bonding (especially Bowlby's) have dominated social thought over the past forty years and created a situation where society believes children are to be exclusively attached to their mothers. This sets up women to feel ultimately responsible in being there for their children at all times and sends a message to children that they are unloved if mom cannot give them this attention. Forna quotes Ann Dally, a psychiatrist, who sarcastically suggests that

> although mothers staying at home with their children remains a popular ideal, 'there is no scientific evidence to justify it on psychological grounds and... If one wanted to look for evidence one might even come up with the suspicion that the era of unbroken and exclusive maternal care has

> produced the most neurotic, disjointed, alienated and drug-addicted generation ever known' (p. 64).

These feelings were articulated by some of the women in this study. Betty says, "Maybe I should have been a nurse. Like, if I had it to live over again I might be a nurse. I always wanted to be a nurse." She appears to have chosen between the two, and accepted that her place was at home with her children. Darlene says,

> I worked for one year for the Manitoba Child Care Association doing some workshops across the province. I quit after about nine months, and I loved that job too because I loved to teach. I just felt that I needed to be home and it didn't do one bit of good, but I just felt like if I was home I could make sure she was in school.

Other women accepted their role of the self-sacrificing mother despite rejection and loneliness. Inga relates her experience,

> I have really found that parenting these kids is a lonely road because even some of my closest friends still don't have a handle on what it is all about, and it is a different parenting style. I mean, the way you would correct, discipline, teach your so-called normal kids is totally different. So, we had a lot of criticism even from our close friends, from our church family, and so on and even to the point where, with an incident last summer, people were saying you need to get rid of that kid, as if it was a dog with rabies or something, so we have been extremely cautious with what we share with other people.

Paula and her partner didn't get much extended family support either. They basically relied on one another. "We basically stuck to ourselves. We've been in prison." Darlene's experience was just as painful in terms of her extended family being unsupportive. "The majority on both sides have said, just let her go, I mean can't you unadopt her or something, she doesn't want to be part of your family. Just send her back where she came from...".

Several women sacrificed their personal health. One woman was diagnosed with post-traumatic stress disorder as a result of the level of stress and ongoing support she had been trying to provide for her daughter for the past eight years. Another two women were told that they suffered from depression brought on by the amount of stress parenting children with FAS/FAE can produce.

Another expectation is that the perfect mother will raise her children in a way that will ensure that by the age of 18 they will be independent, productive members of our society, ready to pull their weight and fulfil their roles as women and men. Karen is very adamant that this needs to change,

> We have a very impatient, intolerant society. We judge and everything is based on how fast and how productive you are and how efficient you are and how much money you can make. ... My daughter is kind and patient and understanding, yah. And to me that is just as good as getting a 96 on a math exam, you now. We need to value different things in people.

All of the mothers wanted to see their children live lives that were fulfilling and happy. Over half of them felt that the way for them to accomplish this was for them to get a job and have some sense of worth and independence. Jane's dream for her daughter was articulated this way. "I think it would be very nice if she could somehow have some kind of a job. So that she would feel as though she were a functioning member of society because I think that she sometimes feels, well, as she said to me just last week, 'I'm just a loser'".

Many of these mothers were continuing to actively advocate for their children even when they were in their twenties and early thirties. It appeared that their advocacy and mothering would continue until these dreams and aspirations were fulfilled. Although, not directly articulated, my sense of these women's feelings of personal success with their children would only be fulfilled if they were able to see them get to a place where they were productive, accepted members of society.

The children with FAS/E that have been identified in this study present parenting challenges and skills that are exhausting, stressful and sometimes overwhelming. Even so these women continue to feel pressure within themselves and from society that they need to be all things to their children, that they need to be the perfect mothers who are able to understand and meet all the needs of the children for whom they provide care. They are continually pressured from within and without to measure their success by their children's approximation to the productive socially accepted member of society however unrealistic that goal may be. Such a laissez-faire attitude towards society's obligation costs dearly in terms of damaged lives; damaged lives both in the sense of women caregivers who find themselves overwhelmed, unsupported, and burnt-out, and damaged lives in the sense of foster children whose ability to celebrate life, discover their strengths and find their place in the larger society has been compromised.

The Child Welfare System

Many of the economic and political institutions in our society depend for their survival on the continuation of the concept of the nuclear family and the place that women hold within the family unit. However, the way in which our society exploits this particular group of women, the women who foster children with FAS/FAE, is even more clear when we consider their place in the child welfare system. Miedema (1998) writes, "Even though they (foster mothers) are the backbone of the child welfare system in Canada, their work is almost completely invisible (p. 304). She goes on to say, that the child welfare system depends upon perpetuating the motherhood myth in order to supply the foster care system with women who will voluntarily care for children that have been removed from the care of their biological parents. "The state encourages women in their views of foster mothering. It wants women to feel good about themselves and to believe that what they do is "good," but not "hard" (p. 312). We could add "applauded" but not "valued".

The women in this study do personify many of the traditional roles. Half of the women interviewed spent the majority of the time while the children were young as stay-at home mothers. Two others worked from the home. Those who worked outside the home all worked within the caring profession, except for a self-employed artist. Their occupations included nursing, teaching, day care workers and co-ordinators, and various social work positions.

The commitment of these foster parents was apparent in their years of experience. They had fostered and/or adopted from 6 to 33 years; the average length of time being 22.5 years. This was calculated from either ongoing fostering or number of years ago since they adopted - even adoption breakdowns had not ended this caring relationship as those who either had to place their children temporarily in foster care or other institutions maintained very strong and ongoing involvement. They also participated in ongoing planning and strategizing for their adolescents and young adults.

Sixteen women were interviewed. All but three are or were married during their experience as foster/adoptive parents. Two had separated from partners during their fostering/adoptive years due to death or marital conflict but the majority of their experience had been in conjunction with a partner. Especially with children prenatally exposed to alcohol the intensity of care involved relies upon the assumption that foster families will be "traditional" families, i.e., heterosexual married couples, a breadwinner and a stay-at-home caregiver. (Meidema, 36)

From this brief depiction of the foster/adoptive mothers in the study, it can be concluded that these women by in large conform to the role society has placed upon them. Their continued willingness to care for these individuals demonstrates, legitimises and sustains the existence of our system of " child welfare".

A feminist critique of the child welfare system assists our understanding of how women within this system are being both exploited and pitted against one another. Miedema (1998) suggests that, "Foster mothers are scrutinised and investigated by the official representatives of the state to be certified "good" mothers, while the foster child is "rescued" by the same agency from a "failed" mother." (p. 311). Swift (1991) takes this one step further

> When children are removed from the care of their mothers, the proposed remedy is the "rescue" of the child(ren) from the mother, usually leading to the substitution of another mother for the original deficient other. That the work and responsibility is passed on to another woman is seldom questioned. (p. 12).

Baukje Miedema writes very pointedly about the way society has pitted biological mothers and foster mothers against one another.

> Not only has the image of the "good" mother (the caring compassionate, self-sacrificing, middle-class woman with good housekeeping skills) been constructed (Swift 1995; Margolis 1984), so has the image of the "bad" mother. The failed mother is an important social construct in the context of foster care, because it is the "good" (foster) mother who typically rescues the child from the "bad" (biological) mother (1999, p. 26).

Miedema goes on to say that the government has reinforced this idea by "seeking out a pool of women who are willing to care for other women's children without receiving any wages for their labour." Most foster-care providers see their caring as an extension of their mothering (1999. p. 45-46).

The following sections will look at some of the ways that the child welfare system has been set up in a way that is exploitive to women and their varying roles within the system. The first section relates to the exploitation of biological mothers, the second to the exploitation of the foster mothers and the third to the manner in which foster mothers and social workers are set up in an unbalanced way thus detracting from the very purpose of child welfare - supporting children and families.

Exploitation of Biological Mothers

Our society focuses and lauds individual characteristics that lead to independence, productivity and material accumulation. Those who cannot live up to these expectations are viewed as problems or irritations. They are blamed for their weaknesses and in this way society is not held responsible for having created institutions and systems that oppress and marginalize them. When women with addictions give birth to children with FAS/FAE it is easy to blame them and totally lose focus on the root of their addictions. That is, the discrimination, the abuse, the marginalization and the hopelessness that is a large part of their reality.

Dr. Edward Connors, at a recent workshop in Winnipeg, Manitoba spoke of the FAS/E disability as it relates to Aboriginal people. Many First Nations' mothers are facing the fact that the abuse of alcohol has caused injury to their children. Their guilt often leads to further self-destructive behaviour. He says that as a society we need to understand First Nations alcohol abuse within the "context of our social and cultural history." (p. 49) It is impossible to speak of FAS/FAE within Manitoba without understanding the impact of colonisation (during which time alcohol was introduced to Aboriginal people), residential schooling and various other attempts at assimilation of the First Nations people. The impact of these various attempts at assimilation stripped them of their traditions, their children (residential schooling and adoptions), parenting skills, and their livelihood. Violence, alcohol abuse, poverty and hopelessness have been some of the results (V. Morrissette, B. McKenzie, L.Morrissette, 1993). If society loses sight of this history it becomes easy to blame Aboriginal women for their addictions and less necessary to take responsibility for addressing systemic inequalities that continue to oppress and marginalize them and pressure them to assimilate.

Poverty and alcoholism create a reality, or perception of a reality, not readily accessible to the researcher who has not shared in the life experience of being poor and marginalized. Recent research, as cited by Aminatta Forna (1999) is beginning to question the cause and number of FAS births.

> ...The link between alcohol and foetal harm may not even be as clear as was previously thought. One carefully controlled study showed that women of lower economic status with poorer nutrition who drank heavily during their pregnancy were almost sixteen times more likely to have children with FAS symptoms than middle-class women who drank the same amount. The crucial factor was food (p. 99- 100).

Research is challenging the traditional understanding of why we see a disproportionate number of fetal alcohol children in poor and marginalized communities in Manitoba. Poverty often means making do with food that is not high in nutritional content. The cheaper food contains many carbohydrates that stop the hunger pains without providing adequate nutrition. Furthermore, persistent poverty and discrimination create hopelessness and despair. Individuals often learn to cope through alcoholism and other escape mechanisms. From this perspective, the problem of FAS/FAE is seen as a product of poverty and discrimination.

The failure to support such women in their struggles to parent and the resulting huge numbers of Aboriginal children that are brought into care only continues to marginalize and disempower this population and to further perpetuate the assimilation process.

Our child welfare system is based on a model of substitute mothering. The biological mothers are cast off as "bad" mothers and are replaced by "good" substitute mothers, usually foster and adoptive mothers (Swift, 1991, p. 311). The mothering that foster and adoptive parents provide is rooted in mother care and not in professional care (p. 308 - Miedema). Biological parents for the most part were removed from the scene. The welfare system and society at large views them as failed or "bad" mothers. All but three of the foster mothers in this study accepted their role as the substitute parent without questions. Darlene had some conflicted feelings about her role. She had made a deliberate effort when her daughter was young to assist the birth mother in learning strategies to parent but this proved to be unsuccessful. Later on, she continued to question whether her Aboriginal daughter would have been better off being cared for by her own extended family rather than her Caucasian family. Two of the Aboriginal mothers, Nancy and Paula never saw themselves as substitute mothers, they were the women who cared for someone else's children and were always open to input and ongoing contact.

This substitution of the mothering role provides little opportunity for family reunification. It creates a situation in which a child is torn between two women who are competing for their love and affection. The relationship is one of conflict, not support and mutual goals. Often when ongoing visitation is provided the child struggles because both women are vying for the position of 'mother'. The child's struggle is noted by well meaning social workers and the end result is often to remove one of the competing parties (the biological mother) in order to relieve the child's turmoil.

This pitting of one mother against another becomes increasingly important when we acknowledge that Aboriginal families and children are grossly over represented in the child welfare system. In Winnipeg between 60 to 70% of the children and families served by the child welfare system are Aboriginal. (WCFS Strategic Planning Workshop) The women interviewed in this study were 75% Caucasian but all had fostered or adopted at least one Aboriginal child. These demographics cannot be ignored especially in light of the cultural and political climate presently in Manitoba. Aboriginal people are in the midst of trying to regain their identity and culture. A large part of their culture revolves around the concept of extended family. Historically, as discussed earlier in this thesis, attempts to assimilate Aboriginal people were conducted through such processes as residential schooling and "the sixties scoop" when Aboriginal children were shipped off all over the world to be placed for adoption.

Assimilation is still occurring within our child welfare system through the process of removing children from their mothers and extended families and placing them within substitute Caucasian families who are unable to help them understand what being Aboriginal means and how to be proud of that heritage.

We need to challenge this continued practice. Both the assimilation process and the devaluing of the work foster mothers do needs to change. One way of doing this could be to professionalize their work. This would exchange the "competition between women for the 'ownership' of children with the concept of shared parenting" (Smith and Smith, 1990, p. 69). This would be a huge step forward in both validating the work that foster mothers do and in removing some of the exploitation of biological mothers. A pilot project in Australia highlighted how this process could happen. A group of women were asked to foster but in the role of a paid service provider, similar to teachers, residential care workers, etc. These foster mothers viewed biological mothers as important women whose wishes were to be honoured (p. 69). Professionalizing the foster mother's role assisted in breaking down the competition for the child's affection.

> Under this system, the foster mother can identify with the problems of the natural mother, and her job satisfaction is related to the rapid return of the child to his or her natural family, when possible, because restoration of the child is the sign of a job well done. In this system the relationship between "an uneasy client-worker status with hidden agendas" to a supervisor or manager and an employee, with strong emphasis on information sharing and teamwork in a manner that highlights their common interests (pp. 69 - 70).

A renewed effort toward working more closely and for extended periods of time to enable the reunification of children with their families is of great importance. The maintenance of family relationships for Aboriginal people is crucial to their goal of self-determination and self-government. Lack of resources and the need for ongoing patient work often cuts efforts short in making these relationships a possibility.

Foster Care and Adoption

The above section not only highlights the exploitative position that child welfare practices imposes on biological mothers but leads to a discussion of the need to challenge our views on the position of foster mothers and adoptive mothers. The discussion up until this point has considered how foster and adoptive mothers have largely accepted and assumed the roles set out by society around mothering and caring for others. However, FAS/E has become a social problem in the past few years that has put ever-increasing pressure on foster parents and adoptive parents. The foster and adoptive parents in this study found that they needed new techniques and alternative disciplining and parenting approaches in order to parent these children. Often, as articulated in this study by many women, they have not been provided with these parenting tools in a proactive way. They have not received adequate information at the time of placement and have not been provided with necessary training. Hanna says that she knew there must be something that she was missing so she

> started reading - every once in awhile there would be an article - and then I started doing some research out at the university. I started to look everything up that I could. So, I started getting some information myself and then started talking with the social worker.

Fran reflects some of the same frustration.

> What I am saying is that I think that when a child who is diagnosed, then foster parents should be handed (clap), this is it, this is what you can read up, this is where you can find out more so when it does get frustrating you can just look and say that is why he is doing this or that. I mean it took me four years to not get so frustrated with him... I mean if I would have had some knowledge about what these kids suffered through being fetal alcohol, them maybe I would have understood a lot more.

A feeling that inadequate information was provided was a very common theme among these foster and adoptive parents. Probably the most blatant example of this can be illustrated in the following example. A question in regards to the amount of information she had received prior to placement was posed.

> Very, very little. Nothing. We knew that the mother had drunk; we didn't know that she was an alcoholic. We weren't given anything about their mental abilities or anything. The first clue we had... well we compared them to other children and so we knew that they weren't progressing as quickly. But the social worker came when they were one year old and asked what the children were doing and I told her and she said, "Oh, they're that retarded after all!" And that was the first we even knew that they had thought they were retarded. They didn't tell us a thing.

And yet, the child welfare system seems to continue to perpetuate the idea that because the substitute caregivers are women and have some experience with parenting, they have the tools that make them able to care for whatever child may be placed with them.

An example of just how low our society values child care can be seen in the following quote: "The skill level thought to be needed by a homemaker, childcare attendant, or nursery school teacher was rated in a recent U.S. Department of Labour publication at only 878 on a scale from 1, the highest skill level, to 887, the lowest (hotel clerks were at 368)" (Held, 1983, p.9). Meyer's (1985) definition of the role of a foster mother cited above should be reconsidered in this context:

> To be a woman, to be a mother, to be lower middle class or poor, to be in a minority group, to work for (with? under?) a child welfare agency, to be paid a pittance, to be asked to parent a child whom no one else is able to parent, to try to love that child and to lose him or her when loving has been achieved, to be supervised by a 22-year old social worker, to have to deal with school teachers, police, courts, medical appointments, angry biological parents, and the impact of all of this upon one's own family – that is the lot and life of a typical foster mother in America. Any one of the status's mentioned would be sufficient to qualify foster mothers for victim status – that is, being a woman, a mother, lower middle class or poor, or a member of an ethnic minority – but when taken together they are, as is said, quite a lot on her plate (p. 252).

This quote may sound a little melodramatic at first glance, but in fact it is not. When we consider the value society places on childcare it is readily apparent that foster care providers will be mostly women and that they will not be well paid. Adequate training, support, respite and knowledge about each particular child are often not provided because this knowledge and skill is presumed to be a basic part of the caregiver's inherent 'equipment'. It is viewed as "only women's work and therefore, not that difficult".

Karen explains that parenting a child with FAS/E was not something that came naturally to her at all. Child Development taught her how to survive. With her biological children she allowed her children lots of freedom, and lots of expression. Child Development taught her

> to be more structured and to set really firm boundaries with this child, set guidelines, and they said either lock him in the bedroom or lock yourself in the bedroom, because there were times when I would become so exasperated I felt like such a failure that I knew that there were times that if I put my hands on this kid I could kill him. You know it was... I had that potential - it was really frightening because I didn't have this trouble with my other children, you know. But it didn't seem to matter what I did, and so there were times that locking myself in the bathroom was a wonderful strategy. And I had to learn to be much more consistent, tougher, I became I guess, but I always struggled with it. It wasn't my natural way and I didn't have to do it with any of my other children. And it caused lots of criticism like with other families.

All of these foster mothers and adoptive mothers went into caring for the children placed in their homes believing that the skills that they had were enough. After all, the home studies and messages from the system did not insist on other skills or relate that they needed additional training.

Most have learned specialised skills through experience, through networking, through courses they have registered in and often paid for themselves, and through consultants they have paid to see. The training and preparation from the welfare system has not kept pace with the high needs of these children. It continues to send the message that fostering or adopting is not a profession but simply an extension of mothering that any nurturing, caring women in a nuclear middle-class family can provide.

This lack of information, lack of necessary training and skill development and the lack of resources that many institutions fail to provide to these children and adults are exploitative to these foster and adoptive mothers. Their efforts are not being recognized as work, their power is diminished by the lack of status they hold in the welfare system, they are not being economically compensated, their choices to work outside of the home are being restricted by the high demands of caring for a disabled person and they are made to feel like failures by many professionals who view the adolescents struggles as a result of inadequate mothering. The child welfare system is de facto perpetuating the myths that caregiving is women's work, that it does not require any expertise, education or valued skill; that women should work for love without compensation.

One alternative would be to professionalize foster care, train foster parents to do a job specific to the children's needs and pay them as professionals. It was a surprise for this researcher not to hear many foster parents complaining that they were not paid enough. This is more clearly understood if we take a closer look at how their mothering is being compensated.

Most foster parents with children disabled by FAS/FAE are being provided with special rates. It could be concluded that this is good and that it is a sign that their efforts are being recognized and their skills are being justly rewarded, however, this is not the case. These rates are based on the children's difficulties and not on the skills that foster mothers have trained for and developed. Further, it places these mothers in a situation where they need to "complain about" the negative aspects of their foster children in order to justify a special rate that reflects the kind of work and skill they must provide. This focus perpetuates the notion that these children are a "social problem" and again fails to recognize that the social problems lie not in the children but within a system that fails to provide the resources to address the addictions, racism and poverty it created.

These special rates, although certainly not in most cases compensating for the skill and work that is put into providing for these children, have served to quiet these women and deflect attention from the inequality that exists within the child welfare system which continues to exploit these women.

A second alternative is to provide adoptive mothers with a subsidy when they adopt children with FAS/FAE. This financial remuneration would at least to some extent provide monies for any extra resources, such as tutors, psychologists, therapists, mentors, occupational therapists, etc. that may be necessary for the child as they journey through childhood and adolescence.

Women Social Workers

It should be noted that there is also a third level of inequality that is at play within the child welfare system. This inequality sets up social workers (mostly women) in a place where they are to be the experts about the children with FAS/FAE in foster and adoptive care. The expertise and merit of the positions taken by foster caregivers is often apparent to them. At the same time, they often find themselves powerless to influence or change bureaucratic systems (mostly run by men) that restrict necessary resources and supports being provided to this population group and their care providers.

Instead these social workers often find themselves in the position of attempting to justify the meagre services provided, or being told to challenge the need for, or place unrealistic barriers in the way of, the requested services on behalf of the bureaucracy.

Miedema (1999) notes that the inequity that exists between foster/adoptive women and social workers is primarily enforced by the lack of viewing foster care (and I would add adoptive mothers of children with FAS/FAE) as a professional service.

> Although the foster mothers care for the children around the clock, legally they are not the parent and therefore are often relegated to the fringes of important decisions affecting the foster child. It is the experts, the social workers, who are entrusted with the long-term planning for the child. This is a rather incoherent arrangement at best and precarious at worst for the foster child (p. 79).

Many of the women in this study spoke about wanting to be treated as experts because they felt they often were placed in a role of teaching new social workers about FAS/E, about the particular children in their care and about the parenting techniques that did and did not work for their particular children.

Hanna puts this very well.

> I think that social workers have to start recognising parents as experts and including the parents in decision making and in problem solving. I think too often social workers go into a home to tell the foster parents how they should be doing things rather than going in to problem solve with them. And don't come in as the experts because I think that often is intimidating for people and foster parents won't share the same ideas then unless they are experienced and have done a lot of it and feel confident. But I think you will find that foster parents probably already started to learn a lot of things that do work. At least they will be able to give you ideas of difficulties they are having and things that they think might be suitable. Our experience was that there seemed to be more of a tendency to (and not just from the Agency but teachers too) to downplay or devalue what the

> foster parents or parents (often they are natural parents too) what they are experiencing. I think they should be working more as a team rather than coming in as the experts.

If foster care and subsidized adoption were to be viewed as professional services this inequality could be changed and foster and adoptive parents as well as all other professionals working with children, adolescents and adults prenatally exposed to alcohol, could be seen as a team working to best meet the needs of this population. Together, they would be able to come to an understanding about how to best use scarce resources in a way that would provide maximum benefit to individuals with FAS/E. It would also assist in bring these groups of women together - social workers and foster/adoptive mothers - in order to have a united voice in advocating for necessary changes and implementation of necessary services for these individuals.

Challenging the Nuclear Family Concept of Caring for Children with FAS/FAE

The single most pressing concern that these foster and adoptive mothers presented in the interviews shapes the final discussion that needs to take place within this thesis. The concern was that the extended community supports neither them, nor the children they parent. This cry for support also reflects the concerns raised by the feminist critique that informs much of the discussion in this paper. Caring for children and particularly caring for a disabled person needs to be a community effort and should not be relegated solely to mothers. Placing the onus on mothers is exploitative and ineffective.

Unfortunately, as Baines, Evans and Neysmith (1998) point out, there has been an increasing push in the past few years to privatise, to cut back on social programming. These cuts, they say, "are typically accompanied by neo-conservative praise for family-based care and the creation of moral panic about the destruction of 'the family' (Pateman, 1992: 231; Luxton, 1997: 23) p. 13. As a society we need to challenge this perspective and acknowledge that looking after those effected by FAS/E is a community responsibility. Young (1998) suggest some ideas about how this can occur.

> A greater degree of mutuality in relationships and collective co-operation are identified as a keystone to redistributing the costs and benefits among men, women, markets, and states. Many feminists suggest, for example, that an ethic of care emphasising interdependence and responsibility must be integrated into the highly individualised, rights-oriented approach that underlies our traditional conception of justice (Young, 1992 as quoted in Baines, Evans, Neysmith, p. 16).

The place to begin would be to stop blaming the individual mothers who gave birth to children with FAS/FAE, but to rather look at the societal systems and structures that marginalize and oppress women and take ownership and responsibility for this issue.

Once this responsibility was collectively owned, society could embrace the mothers and all other individuals and systems that impact on the individual with FAS/FAE to work for the common goal of health and maximum fulfilment for both of these populations.

The desire shown by the foster and adoptive parents, in this study, to advocate and ensure that they are part of the decision making for these children and adults is a necessary component in making this issue a community issue. Community involvement means that there needs to be input and shared decision making at every level. The hierarchy of decision making and the inflexibility of policies needs to be removed in order for communities to take a collective stance in understanding and incorporating an individual with FAS/FAE into its community membership.

It means both giving an equal amount of decision making power to not only FAS/E caregivers and individuals but also giving them choices and alternatives. As Baines, Evans and Neysmith (1998) so adequately put it,

> ...the first question must *not* be how much care can family members provide?... Recognizing that the welfare of children and adults with physical or cognitive limitations is a collective concern would move beyond bolstering the stretched resources of 'family' to ensuring that policies are enacted to promote the quality of life of all Canadian citizens no matter what the configuration of the households within which they live. (p. 17)

This shift away from the nuclear family concept to a more community based approach could encompass such models as the aforementioned shared-parenting approach, extended family approaches and any other creative options that ensure respectful, supported, and equitable frameworks. It would mean that communities could collectively come to an understanding of what is needed by the individual with FAS/FAE and pull in resources from every discipline to ensure the required support is in place.

It should not be overlooked that this wider ethic of shared caring is very much in accord with Aboriginal values and traditions. However, fundamental to the implementation of a move toward collective responsibility is recognition that the young, the elderly and the disabled are valuable, worthwhile citizens and that their participation within our society is needed and important. When this is recognized, then and only then, will the ethic of caring be seen as a valuable, worthy endeavour that needs to equally be shared by men and women as well as the entire community.

Here, in Winnipeg and throughout Manitoba there is much opportunity to learn about community based caring and living from Aboriginal peoples. Their traditional way of life centres on relationships. That is relationships with the universe and all things within it, the Creator, and one another. Communities traditionally embraced each and every member, recognising their gifts and strengths regardless of physical, cognitive or emotional deficits. It is a model that focuses on strengths rather than on problems. Persons with FAS/FAE, in this approach would be incorporated into the community in ways that both furthered the good of the whole community and empowered the individual to use his/her own gifts. V. Morrissette, B. McKenzie and L. Morrissette (1993) write:

> The development of Aboriginal culture involved the exercise of responsibility on the part of all members for the benefit of the group. This interdependence and collective approach to responsibility contrasts with the individual competitiveness that characterises the consumer-oriented dominant society (p. 93).

More communication and discussion with Aboriginal people about how to value and support individuals with FAS/FAE would be an invaluable process. Collective caring in some situations may not mean paying extended family members to care for individuals with FAS/FAE but instead redirecting financial resources to support the community in caring for the individual. This could mean such things as enhancing the educational system, providing supported work opportunities and developing supported living situations.

Although I only had opportunity to interview four Aboriginal/Metis foster and adoptive parents a few differences relating to extended family/community care were apparent. For example, Nancy says, "... its different I guess, in how we foster in the Aboriginal community, we don't, its not so separate.... We work very closely with the families, keep in touch with the families as much as possible you know so even the dad will say, go with the woman who looked after you." Fran says, I feel that all my children should have as much contact with their biological parents, if it is safe, ...because biological mom and myself have a pretty good rapport she'll call me up while (her son) is there and she would say that he was under the influence." Paula says that her foster children's mom is brought to her house to visit the children, "she's come to stay with us for a week at a time".

This same openness and belief that ongoing contact was beneficial was not generally noted with the Caucasian parents. When contact and relationships did occur between the child and the biological families it usually only developed when the adoptive/foster children were teenagers and were initiating it on their own. This is consistent with the nuclear family concept that dominates our western culture. It seems apparent that we could benefit from more closely monitoring and matching our foster placements so they are culturally appropriate.

The above discussion has brought out a number of issues that relate to mothering, foster care and the need for community caring. Women in this study largely took on the role of caregiving for children with FAS/FAE out of an acceptance that their place in society was to provide nurturing for those children unfortunate enough not to have an appropriate mother. Their commitment and personal sacrifice for these children shows both how they have shouldered the ideology that they are to be perfect mothers to them, providing for all their needs, and also shows how we as a society continue to encourage and allow this exploitation and sacrifice to continue through such political systems as the children welfare system. A discussion around professionalizing foster care and looking at the need to move toward community care was also explored.

CHAPTER SIX

Conclusion and Recommendations

Introduction

Like many communities, Winnipeg and the surrounding area are struggling to understand how best to support those who are disabled by FAS/FAE and those who care for them. It was hoped that new ideas and strategies might be gleaned by listening to the expertise shared through these women's voices. In this final chapter I will summarise the findings of this research study and put forward some recommendations and challenges for both social workers and the many other professionals that work with individuals prenatally exposed to alcohol and their care providers. A discussion of the strengths and limitations of this research will be offered as well.

This research study identifies women as the primary caregivers for children and other dependent members of our society. Individuals with FAS/FAE are born with a variety of disabilities and continue to experience difficulties and challenges throughout their life. It is usually women that take on the ongoing responsibility of caring and supporting them. The women caregivers I interviewed were all foster and/or adoptive parents. None of the caregivers were related to the children they adopted or fostered.

Although there are a number of factors, historical and systemic, that impact on women's use of alcohol during pregnancy the usual response is to blame women for causing FAS/E. This is short-sighted and inaccurate when society plays such an important factor in marginalizing and discriminating against many of the women who bear children with FAS/FAE.

FAS/FAE is a life long disability. It is a disability that begins before birth when the developing foetus comes in contact with a teratogen (alcohol). The resulting damage can be physical in nature or cause deficits in the areas of social skills, language, learning or behaviour. There are so many factors that influence the outcome - i.e. nutrition of mom, health of mom, amount of alcohol, stage of development, etc. - that it is difficult to know what damage will be caused. However, it is clear that there is no cure.

The persons with fetal alcohol in this research study were quite representative of the disability. They were all affected quite differently and uniquely. There were some that were mentally challenged and others who were very high functioning intellectually. There were some with obvious physical disabilities and many others with social, learning and behavioural issues. Many were also very gifted in such areas as athletics, handicrafts or music.

It is difficult to give the exact number of individuals with FAS/FAE referred to by the caregivers in this study as the women had cared for many persons with this disability. However, of the primary ones discussed, seven were female and thirteen were male. Two of the males had committed suicide. Three of the females were struggling with stability, and four were doing fairly well. Two of the females who were doing well were mentally challenged. Five of the eleven males were struggling with ‘out of control’ behaviour and six were doing well. Four of the males who were doing well were severely damaged, that is, they were mentally challenged.

The caring needs of the adoptive and foster parents also varied. A few of the persons effected by fetal alcohol exposure were able to function, for the most part, on their own once they became adults. The responsibilities of their caregivers were somewhat reduced. The majority, however, had either some ongoing support requirements or major supports were needed. Regardless, the adolescent years were fraught with worries, questions and struggles as the women endeavoured to garner understanding and to find services for the children they were raising.

Feminist Critique

The caring of others has been relegated to women in Western society (Guberman, 1990; Forna, 1998; Baines, Evans, and Neysmith, 1991; Abramovitz, 1988 and Graham, 1983). According to Baines, Evans, and Neysmith (1998) this assumption "continues to underpin policies, programs and practice (p. 4). One very striking example of how policies, programs and practice perpetuate the relegation of care to women is seen in the child welfare system. When biological mothers are deemed unable or unfit to care for their children our society finds other mothers to fulfil this nurturing role. This critical role in maintaining our society's child welfare programming is given little value or recognition. Instead of supporting and partaking in the care of these individuals, society continues to criticise and blame women (now substitute caregivers) when children, adolescents and young adults cannot manage to keep pace with societal expectation.

The women caregivers in this study exhibited some common features in their journey of caring for children, adolescents, and adults with FAS/FAE. These included the following:

1) The women in this research study were all very committed and caring mothers. All of the adoptive parents and the majority of foster parents saw their role as mother to these children as a life long commitment.

2) The mothers in this study were required to take on a major advocacy role to try and help systems and society in general understand why their children were struggling.

3) The mothers in this study were able to see the gifts and talents that their children brought to the world despite their many behavioural and cognitive challenges.

4) The mothers in this study sometimes struggled with health problems, relationship problems, or gave up career opportunities as a result of the intense care that was needed to provide for these adolescents and adults.

5) The mothers in this study maintained a commitment to the children despite lack of resources, lack of knowledge of the disability they were dealing with, lack of adequate remuneration and recognition from the child welfare agency or from society in general and sometimes despite lack of support from family and friends

6) The majority of the foster and adoptive mothers expressed guilt and remorse for not having parented more appropriately prior to understanding their child's disability despite the fact that they apparently had no way of knowing how to do things differently.

7) Not one of the mothers indicated that they would choose not to parent the person(s) with FAS/FAE again if given the opportunity to make a choice.

Women have been given the responsibility of raising independent productive members of society who will be ready at approximately the age of eighteen to fulfil their society roles as women and men. The reality that this population often cannot participate in a competitive capitalistic society leaves these mothers open to charges of failure, blame and criticism. In addition, by not supplying adequate resources, services, and remuneration we, as a society, exploit women who care for persons with FAS/FAE even further. Society counts on them to provide care out of social responsibility and because of the humanity, the compassion, the caring, and the devotion that emotionally bonds them to the child. As a result they continue to care, advocate and support these persons well beyond the age of majority.

Summary of Research Questions

The research questions in this study were twofold. One set of questions explored the challenges of the women who were providing care to individuals with FAS/FAE. The second set of questions sought to more fully explore the accessibility and adequacy of the knowledge and resources that these women and their children encountered. These foster and adoptive parents were asked to give their perspective on these questions because their expertise is valued and it was anticipated they would know what is needed and what the cost maybe if these supports and services are not put in place.

The first group of questions sought to gain a clearer understanding of the challenges women substitute caregivers are experiencing as they care for individuals affected by FAS/E. It became clear that the tasks and responsibilities that are specific to the care of individuals with FAS/FAE go beyond the care requirements of 'regular' mothering. There is a need for ongoing close supervision. Because these individuals often cannot generalise from one situation to the next they need reminders and cues as to consequences and outcomes, they require super human patience, they need established consistent structure, they need patient and persistent repetition in order for learning to make its way into long-term memory, and they need advocacy with the school system and other systems to foster these same skill sets among teachers and other professionals.

Another part of the first group of questions sought to understand if there were personal costs to these women in terms of their, physical, emotional, mental and social well-being. Although not always implicitly stated, the costs to many of these women in terms of personal and family time were tremendous. Some of the women left jobs to stay at home with their children because they felt this might better meet their child's needs. Some experienced relationship problems. A few women stated that the other children in the home felt that they were being ignored or the children with FAS/FAE were being favoured because of the extra time dedicated to parenting the child(ren) with FAS/FAE. Some women suffered from depression or post-traumatic stress disorder. Family shunned others. Many stated that their social life was quite limited because of the ongoing supervision needs and the difficulty in finding skilled/knowledgeable people to provide respite.

The women were asked how they felt about the care they had provided. Many had mixed feelings. Some of the women carry a sense of guilt. Prior to understanding why their children were acting differently, many felt that they had been too impatient, too unstructured in their parenting and too demanding. Fortunately, many have been able to work through some of this guilt and are feeling a healthy sense of mastery around knowing what is best for their child.

Another question asked if they felt their work was valued by society. Most of the women interviewed felt that their work caring for these children was undervalued. This was not expressed in terms of them feeling they were not being paid enough. However, they did feel that many other professionals and societal members were quick to blame them when their children were behaving in unacceptable ways. It was largely a matter of people not understanding the difficulties that these children were experiencing and having a need to point the finger at someone in an attempt to clear themselves of any feelings of guilt or obligation to find creative solutions to assist them.

The women were also asked about the joys and the burdens involved in looking after these children. The women found that parenting these children brought them much joy. One way that this was expressed was in relation to the many talents and personal attributes that these persons developed. Some were enheartened by the journey of actually caring for them and seeing the progress and maturity their children gained when their futures had originally been predicted as pretty bleak.

Many of the burdens that these women expressed were imposed upon them in the form of inflexible systems policies, lack of information, and lack of monetary funding. As a result their children's needs were not adequately addressed in areas such as schooling, employment, mental health and community living.

In the second set of questions, the study was seeking to understand how these women were being supported and what services were presently in place to assist individuals with FAS/FAE and their caregivers. Most women found that the existing services were not adequate to serve the needs of their children or themselves.

The women were asked about the supports they received from family, social workers, and others. Several women had no support at all from extended family while others relied heavily on extended family. For those with little or no extended family support it was very lonely. Others found support through friends or ad hoc support networks of other foster/adoptive parents. A few found professional support to be helpful. Most found that they had to strongly advocate for or almost fight to access appropriate services for their children as they grew.

They were asked if present services were adequate. They felt that present services were not adequate in supporting their adolescents and young adults. The main areas that needed to be changed included such things as developing individual learning programs, creating specialised supported living programs, alternative sentencing through the legal system, more support and respite through the child welfare system and creating supportive work environments. Because of this lack of service and commitment to the needs of these children, many women felt that society placed a low value on these children's lives.

Questions in regard to knowledge and training about FAS/E were asked. For most of the women in the study, accessing the knowledge and skills they needed to care for their children had been a long hard road. Many of the women had researched and learned about their child(ren)'s disability on their own. Others had attended workshops and relied on their own experience and the experience of other foster/adoptive parents. A few felt that social workers had been helpful. Most felt that ongoing learning was needed because of the variations in the damage caused by FAS/FAE. Workshops, trial and error and listening to the experiences of others were some of the best ways to keep up-to-date with new strategies and interventions. All of the women felt that the child welfare agency should be providing more training for them, other foster/adoptive parents and for the workers themselves. Several of them felt strongly that many foster/adoptive parents are experts in understanding this disability and they could provide some valuable training and encouragement to others.

I was surprised that more women were not angered by a system that did not provide adequate financial remuneration for the valuable work that they provide. Instead, they have accepted that the special rate that they receive, conditional on the difficulties that their children exhibit is recognition enough. Unfortunately this rate underlines the negative attributes of the children and adolescents they care for instead of recognising the skills and hard work of the care providers.

The above summary points to the stress that many of the women care providers felt in trying to access services for their children. This stress and responsibility needs to be carried more equitably by the community and the state rather than solely by these caring and committed individuals. Perhaps by bearing more of the responsibility society can reduce some of the exploitation presently imposed upon them.

This researcher was somewhat surprised and disturbed by the number of young adult suicides that were present in such a small study. Two young males in this study and a number of other adolescents/young adults with FAS/FAE that these foster/adoptive parents knew about had committed suicide. One of the women interviewed said that in her circle of acquaintances she knew of five young people with FAS/FAE who had committed suicide (Inga). The pain and hopelessness that many of them feel because they have no place in our fast pace society is clear. This, if not changed, will breed anger and despair which when turned outward will result in ongoing dysfunctional behaviour (perhaps criminal activity or addictions that can lead to more children with FAS/FAE) or turned inward which can result in more suicides and mental health problems. Either way the result is costly in turns of the lives of these individuals and the financial cost of supporting them and future generations.

Evaluation of Study

Strengths

One of the greatest strengths of this study was that it allowed the women who cared for individuals with FAS/FAE to give voice to their experience. Through the use of the qualitative research method I was able to dialogue with the caregivers about what their children need as they reach the age of adulthood. The women interviewed offered enough detail and thoughtful answers to be of great value. Their experiences add voice to the challenge that society must face around collective caring for children, the elderly and the disabled in our society. The information they shared also enables us to look at potential ways in which city and provincial programs can be expanded and adjusted in order to support their efforts in caring for persons affected by FAS/FAE.

Adding to the strength of the research is the feedback from one woman who is both a foster and adoptive mother of adult children with FAS/FAE. She has also worked as a foster care support worker and supervisor for over twenty years. She validated that the findings in this thesis rang true both to her experience and the experiences of many of the foster and adoptive parents she has befriended and supported.

Overall, I was able to develop a good rapport with the women interviewed. This added strength and validity to the research, as the women appeared to be open and honest about both their struggles and their successes.

Limitations

My own biases certainly impacted the findings in this study. I struggle with placing Aboriginal children in Caucasian foster/adoptive homes and I struggle with the exploitation of women in providing voluntary care for these very diverse and challenging persons. I attempted to be as neutral as possible about these biases, placing great emphasis on listening carefully to what the women had to say, what they could teach me, and did not argue or contradict their opinions.

The sample size was small and restricted solely to adoptive and foster care providers. Because of these restrictions it limits the ability to make any major generalisations to the broader population.

A further limitation in the research was the inability to have a sample of officially diagnosed individuals with FAS/FAE. Some of the persons represented in the study had been diagnosed by a geneticist, others by psychologists and still others had no official diagnosis.

An attempt was made to hear from women of different ethnic backgrounds, in particular Aboriginal women. Two Aboriginal and two Metis women were interviewed which added some strength to the study. It had been hoped that more Aboriginal women could have been included. The study is, however, reflective of the Child and Family resource pool. The majority of the children in care are Aboriginal and the majority of our foster parents are Caucasian.

Recommendations

An evaluation of the dialogue with these female caregivers and an evaluation of the feminist critique points toward a number of recommendations in the areas of education, social work practice, legal legislation, and policy.

Education

This study indicated that many professionals are still struggling to understand what FAS/E means and how to work effectively with individuals who have this disability. All professionals and people who come into contact and have influence on people effected by prenatal exposure to alcohol need to have knowledge and education about the disability. They need to understand and appreciate the challenges that this disability places on people on a daily basis.

This same education and knowledge needs to go beyond understanding the individual with FAS/FAE to understanding that the community shares in the responsibility of providing care for this population. Professionals and indeed the larger society in general needs to gain a clearer understanding of how difficult this parenting can be and that when it is not shared it can impact in very overwhelming ways on women's lives.

Social Work Practice

The research in this study indicates that parenting individuals with FAS/E is a challenging and extended commitment that goes beyond the age of majority. Social workers and others working with foster and adoptive parents need to be sensitive and understanding of the fact that there are going to be difficult times. Blaming mothers for behaviour problems and prematurely removing children from overwhelmed caregivers should not be considered an answer to the cries for support and help that are sometimes brought forward.

Social workers and other service providers must listen carefully to the voices of the women who care for individuals with FAS/FAE and recognize their expertise. Through listening we as a community can better understand what they need and how we can support them as they endeavour to provide the best care possible for this population.

Their knowledge and expertise is also invaluable in determining the direction and need for new policies and programs required for this population.

Policy

There is a general need to challenge present policies that perpetuate the assumption that mothers need to be solely responsible for caring for individuals unable to live independently. These gender-related expectations need to be replaced with equitable and shared responsibility frameworks that promote community based accountability and caring.

Several current institutional policies need to be carefully explored and changed in order to promote more equitable and creative efforts at supporting those advocating and caring for individuals with FAS/E.

The Medical System

Consideration needs to be given to setting up more specialised psychiatric/psychological services for persons with FAS/FAE. Individuals need to be assessed and understood at an early date in order for necessary resources and services to be put in place. Reassessment, especially in the areas of social adaptability, learning ability and mental health, are also needed as children move into adolescence and then adulthood.

The Educational System

There is a need to evaluate the adequacy of the supports and resources that are available to educate this population group. The educational system needs to ensure that teachers and assistants have the opportunity to know about the individual learning needs of these children. Specific learning methods must include positive reinforcement and achievable goals in order that self-esteem is kept healthy and intact. The educational system must ensure that teachers are given room to be flexible enough to accommodate learning on an individual basis. In order to do this more funding and resources must be made available to the school systems. Many children with FAS/FAE may reach a plateau in their academic learning but have many other specific talents and abilities that need to be encouraged and strengthened. As Karen said, "We need to value different things in people". Unfortunately, if they are not we will continue to see many of these children reaching adulthood with few life skills and little confidence to face the world. Crime and suicide are too often the end result.

If individualised learning is too difficult to incorporate in the regular school system, consideration should be given to creating separate schools or classes that are geared specifically towards their learning needs. For many persons with FAS/FAE, maturation is slower. Schooling may need to include more than the present system of twelve years. A specific Community College geared toward their learning needs could also be set up in order to help them obtain job readiness.

The Legal System

The justice system needs to look carefully at the idea of alternative sentencing and law enforcement for persons affected by FAS/FAE. Consideration should be given to alternative placement (not within the regular prison population) because individuals with FAS/FAE are often easy victims within the prison system. They also are easily influenced in negative ways when placed in the regular prison setting. Training, social skills development and addiction treatment are some of the programs that need to be offered during incarceration.

The Child Welfare System

Consideration needs to be given to the whole concept of fostering as a profession. It is my recommendation that once foster parents are trained and demonstrate the skills necessary to care for children they should be paid and supported as professionals. Support needs to be readily available and respite needs to be provided in a consistent and planned manner that takes into account the needs and requests of the foster parents. In this way the work and skills of these women will be recognized for their true value.

Foster care orientations should include much more information around how practically to parent children with FAS/FAE. They should also include information about caring for children of a different culture. Policies should reflect and uphold the need for Aboriginal children to be placed with Aboriginal families. Alternative shared parenting arrangements and other creative planning should be prioritised.

Children with FAS/FAE should not be placed in homes prior to training as it sets both the caregivers and the children up for failure. Assessments prior to placing them in homes should be done in order for the maximum amount of information possible to be available to the parents and those helping to support the family.

Some of our experienced and knowledgeable foster and adoptive parents should be hired to train and act as mentors to those who are just beginning to parent some of the challenging children in the system. Ongoing training and skill development should be an essential component to the fostering role.

Policies around placing children with FAS/FAE need to be careful considered. Placing children with FAS/FAE for adoption should only be done if prospective adoptive parents are made fully aware of all the struggles and possible challenges that these children may present. Adoption should not be viewed by Child Welfare Agencies as the answer to the financial crunch in terms of not having to put out any more money for those children who are legally and permanently removed from their parent's care. Adoption of children with FAS/FAE should only occur if there are culturally appropriate homes and then only if subsidies are available. This would ensure that extra monies are available for the necessary resources and supports that may become apparent as the individual with FAS/FAE matures.

Consideration also needs to be given to providing a specific facility for adolescents with FAS/FAE who become out of the control of their caregivers and are getting into behaviours that are putting themselves and others at risk. This facility would need to have highly trained staff that understand all the challenges and disabilities that adolescents with FAS/FAE can exhibit. This facility would need to be a locked setting and provide parents with maximum input in order for them to continue to be a major part of their children's lives. The hope would be to return the adolescent home to his/her parents once stabilisation had occurred.

Consideration should also be given to reinstating the Foster Parent Association in the province of Manitoba in order to provide support and up-to-date information to foster parents. (There is indication that this process has begun although nothing has been formally announced.)

Adult Services

Consideration needs to be given to making supervised living settings more accessible to individuals with FAS/FAE. Regular IQ testing does not indicate the level of disability a person has in the areas of social skills and social adaptability. Many persons with FAS/FAE do not have the independent living skills, the memory skills or the emotional maturity to live independently although an averaging of their IQ may indicate otherwise. Supervised living settings could offer a degree of supervision through a live-in case manager who could assist in such things as money management, decision-making and crisis management. This would also help to address the sense of loneliness that many individuals with FAS/FAE feel.

Consideration also needs to be given to making work available to these individuals. This could be done through special supervised work placements that were cost shared by the government and the employer. Allowance would need to be made for difficulties such as focusing problems, pacing of the work and supervision.

For those individuals that cannot work, consideration should be given to make the system somewhat more flexible to accommodate the needs of the individual and the recommendations of the parents. The first criterion would be to recognize that these individuals might never be able to work even though they do not have a visible disability. At that point, some of the suggestions from the parents such as emergency food vouchers or more flexible housing arrangements could be considered.

Consideration also needs to be given to providing flexible treatment services for those individuals who are struggling with addictions. There needs to be a willingness to accept that treatment might fail a number of times but that the service is still available for them. A safe house concept would also be very beneficial for individuals with FAS/FAE. They are a very vulnerable population so consideration would need to be made to finding ways to staff and run the facility in a way that provided safety and structure.

Overall, through tangible and practical measures, women must be given the tools and the recognition that their work and devotion to these individuals is valued and important.

Prospects for Further Research

There is a need for further research in a number of areas. Socially and economically we need to research and implement practical solutions that will combat poverty and social injustice so that the marginalization and blaming of women for disabilities such as FAS/FAE will stop. Until more attention is paid to these issues children will continue to be born with this disability.

The whole supposition of viewing foster and adoptive care (especially in regards to special needs children) as exploitation needs to be researched further. This study only touched on this issue. Effective ways of supporting, training and providing financial remuneration need to be researched and implemented.

More longitudinal studies on how both care providers and individuals with FAS/FAE are doing as they age and as the system changes also need to be carried out. Research needs to be ongoing to keep abreast with techniques, services, and ideas that work at supporting and caring for both the care providers and persons with FAS/FAE in order to ensure that progress and support is being made available.

Various concepts of community caring need to be explored more fully in an attempt to understand how we can more collectively care for individuals effected by alcohol. This would include respectful communication with some of the Aboriginal and other ethnic communities right here in Winnipeg and surrounding area both to understand how their efforts can be more fully supported and how we can build community networking within the regular mainstream population.

Ongoing physiological and biological research is also needed in an attempt to further understand this disability and learn how to best work with those individuals effected. Medications may be found that assist more effectively with the attention deficit problems or ward off some of the depression that some parents noticed in their children.

In conclusion, this research study sought out the voices of women who provide care for adolescents and young adults affected by prenatal exposure to alcohol. The research revealed that there are a number of very strong women in the Winnipeg area who have committed themselves to advocating and caring for this disabled population, sometimes at the peril of their own health, emotional, and/or social well-being. An analysis of this caregiving reveals that these women are being exploited by the systemic and political structures within our society. The expectation that these women, within the context of a defined nuclear family setting, can provide all the care needed to adequately provide for individuals with FAS/FAE is unconscionable. Our various systems; education, medical, legal, child welfare, social services all need to work in a coordinated fashion to ensure that there is a place within society for individuals with FAS/FAE to grow, develop and feel that they are useful members of society. Furthermore, greater community support and involvement must be developed, the real and practical involvement of men and women, related and unrelated. The work of caring for these individuals cannot continue to be placed solely on the backs of individual women. Our society needs to seek and support more creative and useful ways to embrace persons with FAS/FAE as valuable members of our societal community. In the longer term, society bears the responsibility of finding creative solutions to poverty, racism and the other forms of marginalization that underlie women's alcoholism. FAS/FAE is a complex issue that requires a multi-faceted response from every sector of society in order for any noticeable impact to occur.

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______. Winnipeg Child and Family Services Strategic Planning Workshop Information Package, April 1998.

Appendix 1 Final page of FAS/FAE Survey

Thank you for completing this survey. **All responses will remain strictly confidential.** Your survey responses will be combined with those of others to develop profiles of FAS/FAE service needs and gaps in the province of Manitoba. These profiles will be useful in developing plans and priorities for improving services for children, youth and adults with FAS/FAE.

A summary of the findings of this survey should be available by March 1998. You may request a copy by writing to the address listed below at that time.

In order to maintain your confidentiality, this page of the survey will be separated from the answer pages. If you wish to participate in any of the following, you need to include your name and address on this page.

☐ I wish to receive updates and information on FAS/FAE. Please add my name to the Coalition on Alcohol and Pregnancy (CAP) mailing list.

☐ Please provide me with a contact name in my community who is willing to share information concerning FAS/FAE.

☐ I am willing to participate in future surveys or interviews about services for children, youth and/or adults with FAS/FAE.

Name____

Address____

____

____

Postal Code____________ Phone____________________

☐ I am the parent or guardian of individuals with FAS/FAE of these ages:

Check all that apply.

Children under age 5 .... ☐

Children age 6-12 .... ☐

Youth age 13-17 .... ☐

Adults age 18 and over .... ☐

Please feel free to copy this survey and pass it on to other parents/guardians of individuals with FAS/FAE, who would be interested in sharing their experiences.

Please return surveys to:

FAS/FAE Survey
100-233 Portage Avenue,
Winnipeg, Manitoba R3B 2A7

Appendix 2 Letter to Chairperson of the Coalition on Alcohol and Pregnancy

Holly Gammon
7 Bannerman Ave
Winnipeg, Mb.
R2W 0S9

Dale Kendel
Chairperson, Coalition on Alcohol and Pregnancy
210-500 Portage Ave
Winnipeg, Mb.
R3C 3X1

September 14, 1998

Dear Mr. Kendel:

As per our telephone conversation of September 10, 1998, I am writing to seek access to two specific pieces of data from the "Survey of Service Needs in Relation to Fetal Alcohol Syndrome/Fetal Alcohol Effects in Manitoba" that was jointly circulated in January of 1998 by The Coalition on Alcohol and Pregnancy and the Youth Secretariat of Manitoba.

Having established that I wished to undertake a study of FAS/FAE adolescents and young adults for a MSW Thesis with the University of Manitoba, I met with Kathy Jones in the fall of 1997, because I knew of her expertise in the topic of FAS/FAE. She told me at that time that she was in the process of developing a survey which would look at the needs of individuals with FAS/FAE. We discussed the possibility of adding a back page to the survey in the hope that I would be able to access it for the purpose of my thesis research. It is my understanding that it was added for this purpose. This is the information that I am now asking to access. I need a letter from you confirming that I can indeed access the last page. Once my thesis proposal is approved by the ethics committee I would then request the information from the last page of the survey. I need to have this letter by October 30, 1998.

I am a Master of Social Work student at the University of Manitoba. My faculty advisor is Dr. Lyn Ferguson. (Faculty of Social Work) She can be reached at 474 - 8273. Also sitting on my thesis committee are Ms. Kathy Jones and Dr. Susan

Prentice. In anticipation of completing my degree I am working on my thesis which is a qualitative study of the caregivers who are parenting adolescents and young adults with FAS/FAE. My proposed thesis includes interviewing 15-20 caregivers in order to hear their direct experiences of caring for this particular population. It is my hope to study both the needs of these children in their adolescent and early adult years and the needs of the families who are caring for them. I will then attempt to develop a creative, concrete plan for supporting, training and equipping both families and communities for the ongoing task of supporting those affected by FAS/FAE. I am presently at the stage of preparing my thesis proposal. The University requires me to go before the Ethics Committee for approval of my study and research methods later this fall.

In addition to this, it would enrich my research greatly to have access to the data which directly pertains to alcohol affected Youth aged 13 - 18 and to Adults. This would be most helpful in both doing some comparison work with the data I gather through my proposed research and in supporting some of the conclusions that I will be drawing, upon completion of my work.

I thank you in advance for considering my requests and await your reply. I can be reached by fax at 944 - 4006 or by phone at 944 - 4054.

Sincerely,

Holly Gammon

Appendix 3 Draft Letter from the Youth Secretariat Asking for Authorization to Release Names and Addresses

January 18, 1999

Draft of letter
personalized by name and address

Dear _____________:

RE: ***Survey of Service Needs in Relation to Fetal Alcohol Syndrome/Fetal Alcohol Effect in Manitoba***

In January 1998, the above noted survey was jointly circulated by The Coalition on Alcohol and Pregnancy and the Children and Youth Secretariat. This initiative was undertaken to investigate the types of services that are available and needed in the province of Manitoba.

Thank you for completing this survey. Your confidential response will assist in the development of plans and priorities for improving services for children, youth and adults with FAS/FAE.

Upon completing the survey you had indicated your willingness to participate in future surveys or interviews about services for children, youth and/or adults with FAS/FAE. That is the reason for this correspondence.

The Coalition on Alcohol and Pregnancy, and the Children and Youth Secretariat have received a request from a Master of Social Work student at the University of Manitoba to seek access to survey information for the purpose of thesis research. Governed by the University of Manitoba Ethics Committee, the student is working on a thesis which is a qualitative study of the caregivers who are parenting adolescents and young adults with FAS/FAE.

....2/

For reasons of confidentiality, specific information gathered in the January 1998 survey cannot, nor will not, be released. However, if you would be interested in participating in the research to be undertaken by the University of Manitoba Master of Social Work student, please return the ***the consent to release information form*** in the enclosed self-addressed stamped envelope ***by February 7, 1999,*** and your name will be forwarded.

Should you have any questions regarding this matter, please contact Kathleen McMillan, Policy and Program Consultant with the Children and Youth Secretariat at 945-3619.

Sincerely,	Sincerely,
Dale Kendel	Doris Mae Oulton
Chairperson	Chief Executive Officer
Coalition on Alcohol and Pregnancy	Children and Youth Secretariat

encl.

Authorization to Release Name and Address

I understand that information gathered from the *"Survey of Service Needs in Relation to Fetal Alcohol Syndrome/Fetal Alcohol Effect in Manitoba"* (February 1998) undertaken jointly by The Coalition on Alcohol and Pregnancy, and the Children and Youth Secretariat is treated as confidential, and further, that this initiative will not give access to, reveal or disclose, and shall not permit anyone to give access to, reveal or disclose, personal information about you or your family to any other agency, corporation, business, organization, entity or person, without your voluntary and informed consent.

Consent to Release Information

I, ______________________________, give my permission for The Coalition on Alcohol and Pregnancy, and the Children and Youth Secretariat, to release my *Name, Address* and *Phone Number*

TO: ***Holly Gammon***
Master of Social Work Student
(University of Manitoba)

For the purpose of undertaking a study of FAS/FAE adolescents and young adults for a MSW Thesis with the University of Manitoba.

I understand that I can withdraw this consent at any time.

DATE: ____________________ **Phone:** ____________________

Name: ____________________ **Signature:** ____________________

Address: ____________________ **Witness:** ____________________

____

Postal Code: ____________________

** It is very important that consent forms be returned by February 7, 1999.*

Appendix 4 Summary of Findings of the Manitoba Survey of Needs Regarding Fetal Alcohol Syndrome/Effects

SUMMARY OF FINDINGS OF THE MANITOBA SURVEY OF NEEDS REGARDING FETAL ALCOHOL SYNDROME / EFFECTS

CHILDREN AND YOUTH SECRETARIAT

COALITION ON ALCOHOL AND PREGNANCY

COMMUNITY ACTION PROGRAM FOR CHILDREN

Although widely distributed, the survey was not administered in a controlled or scientific fashion and it is not possible to identify survey response rates or to assign precise levels of statistical confidence to the results.

Survey results may serve to identify some priorities for short-term actions, as well as some topics or issues worthy of more rigorous research.

Summary of Findings
For Discussion of Implications

Health Services (References: pages 8,9,11,19,26)

Parents and service providers alike indicated the need for more accessibility to diagnosis for FAS/E, particularly in Northern and Southern areas of Manitoba outside of Winnipeg.

- Parents indicated that 24% of children were not formally diagnosed, but were suspected as being effected by FAS/E through combinations of other factors, particularly behavioral issues and birth parent alcohol histories.

- Child Development Clinic and Geneticists are doing most of the diagnostic services (78.3% of 170 individuals identified as diagnosed in the survey). Pediatricians accounted for a further 15.3% of diagnosed children in the survey.

Services to Preschool Children (References: pages 16,19,24,25,26)

Service and support needs for children under 6 years of age were generally not identified as strongly as for other age groups. However, those which were identified by parents and service providers for this age group gave priority to the following, in addition to the need for diagnostic services:

- supports in day care
- 24 hour crisis support services
- respite services
- play therapy (social adaptive therapy)
- speech therapy
- psychological/psychiatric services

Services to School-aged Children (References: pages 16,25,26,31)

Findings indicated that in general, school-aged children required increased appropriate classroom and day care supports and 24 hour crisis support services for children affected by FAS/E.

Particular regional responses to these needs were characterized by the following:

Winnipeg and Southern Manitoba:

- Parents identified special education services, respite and speech therapy, with respite being the highest need.
- Service providers identified vocational training and transition planning to adulthood as needing emphasis, as well as community based supports such

as parent support groups and peer advocacy.

Northern Manitoba:

- Parent priorities included special education, aide supports in school or day care and respite.
- Service providers emphasized play therapy (social adaption needs) as a high priority.

Services to Youth and Adults (References: pages 16, 24, 25, 26)

Both parents and service providers reported service needs among youth and adults affected by FAS/E more frequently than needs among younger children. Few responses were received concerning services for adults.

- Post-secondary and vocational and educational supports plus supported employment programs were high on both parent/care giver and service provider responses
- Case management, peer support groups, supported living programs were strongly identified as community-based support needs for this population.
- Clinical services were identified as needed by parents and service providers for youth.

Services to Families (References: pages 4,5,6,7,10,11,22,24,25,26,27)

The vast majority (97%) of parental/care giver responses were foster or adoptive parents. For all children reported in the survey 24% were not diagnosed, but 'suspected' FAS/E. Few birth parent responses were received, perhaps not surprisingly as birth parents are not known to readily seek out services (the network largely used for distributing the survey).

- Diagnostic services are targeted on young children. 65% of diagnosed children were 5 years of age or younger, with a further 20% diagnosed between 6 and 12 years of age.

- A significant number of parents reported caring for more than one child with FAS (41%). The majority of these children had been placed in more than one home with 28% experiencing more than five placements.

- Most parents who were using services reported high levels of satisfaction with those services. However, service usage outside of Winnipeg dropped off sharply.

- Case management services (including advocacy services) were identified as needs by parents, with particular emphasis on preferences for joint participation with service providers in decision-making.

- Respite services. availability of psycho/psychiatric services. access to parent support groups were significant needs identified by parent/care givers.

- Parents of older children strongly identified supports needed for supported (community) living, educational and employment programs for their children.

Training-related Issues (References: pages 14,27,28,30,31)

A majority of respondents, parents or service providers alike, reported the need to obtain additional information or training concerning FAS/E issues.

- Many service providers indicated that increased staff training was needed to undertake positive change in their organization with reference to FAS/E services. The lack of financial resources was indicated as the primary barrier to changes in the workplace that would address FAS/E.

- In general, parents considered that they had sufficient information and training regarding FAS/E. A majority of their knowledge came from self-training.

- Parents and service providers indicated desiring training which focused on strategies for living or working with FAS/E children especially for addressing the needs of children under 13 years of age, as well as general public awareness and prevention strategies.

Regional Issues

- Regional differences in survey responses underline the necessity to develop and implement service systems around FAS/E which are coordinated and take into account the particular needs of northern and rural areas of Manitoba.

Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects

Summary of Main Findings

The Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects is a collaborative initiative of the Coalition on Alcohol and Pregnancy (CAP), the Manitoba Children and Youth Secretariat and the Community Action Program for Children (CAPC).

The survey was conducted in January and February of 1998 to obtain the views of parents and caregivers and various types of service providers in relation to the provision of services to individuals with FAS/FAE.

The survey was provincial in scope and attempted to obtain information from parents and service providers located in all areas of Manitoba.

More than 13,000 survey questionnaires were distributed by mail to the following individuals and agencies:

- parents and foster parents,
- provincial school superintendents,
- provincial school education coordinators,
- provincial child day care coordinators,
- school principals and staff,
- individuals contained on the CAP mailing list,
- all child and family service agencies
- all Aboriginal child and family service agencies,
- Head Start projects sponsored by Health Canada,
- Child and Adolescent Community Mental Health,
- provincial health centres and regional health authorities,
- municipal and RCMP police service offices,
- provincial government distribution lists for Health, Family Services, Justice, Northern Affairs and Recreation and Wellness.

Although widely distributed, the survey was not administered in a controlled or scientific fashion and it is not possible to identify survey response rates or to assign precise levels of statistical confidence to the results.

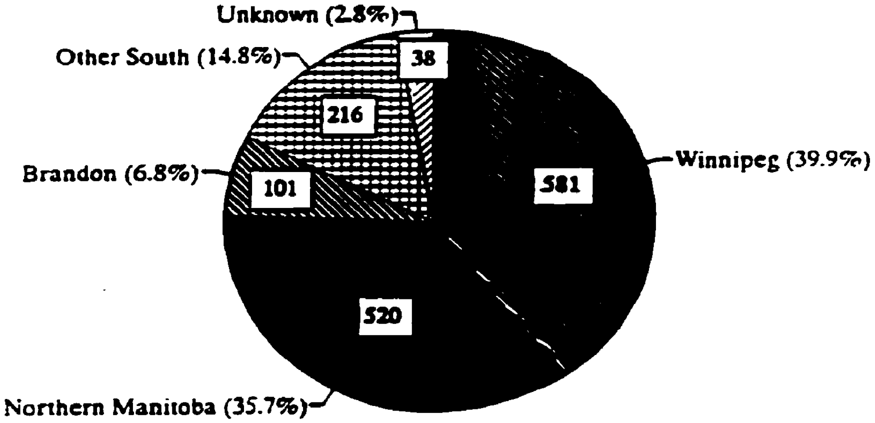
Survey results may serve to identify some priorities for short-term actions, as well as some topics or issues worthy of more rigorous research.

Summary of findings provides highlights of survey responses on five themes, including:

- characteristics of parents and caregivers and the FAS/FAE individuals in their care,
- characteristics of service providers,
- patterns of service availability, service satisfaction and service need,
- workplace changes needed to improve FAS/FAE services, and
- training and information needs of respondents.

A total of 1,456 individuals responded to the survey. About 60 percent of respondents lived or worked in non-Winnipeg locations. Sizable numbers of responses were obtained from both southern and northern residents.

Geographic Distribution of Respondents, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



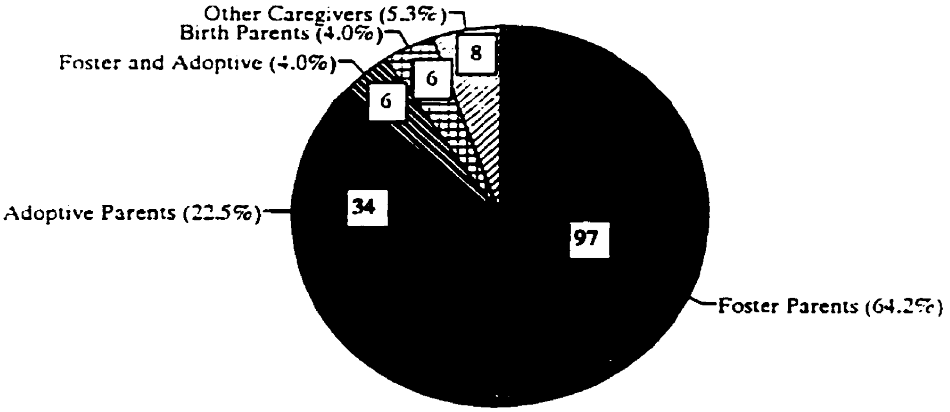
Boxed numbers refer to number of respondents

Specifics

Respondents to the survey included individuals from a wide range of geographic locations. Although residents of Winnipeg formed the largest group (581 individuals or about 40 percent of all respondents), Non-Winnipeg respondents included 520 individuals from northern locations (36 percent), 101 individuals from the City of Brandon (7 percent), and 216 individuals from other southern Manitoba areas (15 percent). About 3 percent of all respondents did not reported their location.

A total of 151 parents or caregivers responded to the survey. Foster and adoptive parents accounted for most respondents from this group. Only six (6) birth parents completed the survey.

Distribution of Parent/Caregiver Survey Respondents by Parent Type, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



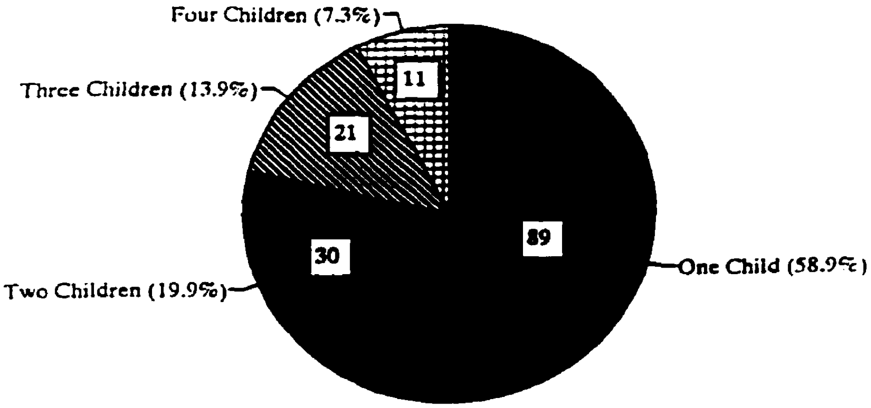
Boxed numbers refer to number of respondents.

Specifics

Foster parents (64 percent) and adoptive parents (23 percent) formed the largest components of parent/caregiver respondents. An additional six (6) individuals (about 4 percent) reported that they were both foster and adoptive parents. Only a small number of birth parents (6 in total) responded to the survey. Other guardians, including relatives or family friends, accounted for the remaining eight caregivers.

The 151 parents or caregivers identified 254 children or young adults who were either diagnosed with or suspected of having FAS/FAE. More than 41 percent of parents or caregivers reported caring for more than one FAS/FAE individual.

Distribution of Parent/Caregiver Survey Respondents by Number of Children in Care, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



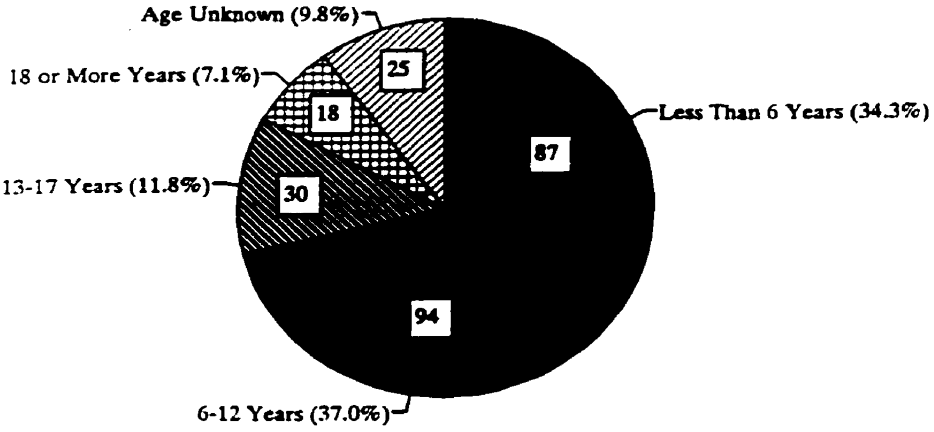
Boxed numbers refer to number of respondents.

Specifics

Respondents to the parent/caregiver survey reported an average of 1.7 individuals either diagnosed with or suspected of having FAS/FAE. Although most parents reported care responsibilities for only one individual, 41 percent reported responsibility for more than one individual. This group included 30 individuals caring for 2 FAS/FAE persons, 21 individuals caring for 3 persons and 11 individuals caring for 4 individuals.

Most (about 71 percent) of the FAS/FAE individuals reported by parents or caregivers were under 13 years of age. Youth (i.e. 13-17 years of age) and young adults accounted for about 12 and 7 percent, respectively of the individuals reported by parents or caregivers.

Distribution of Persons in Care by Age Group, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



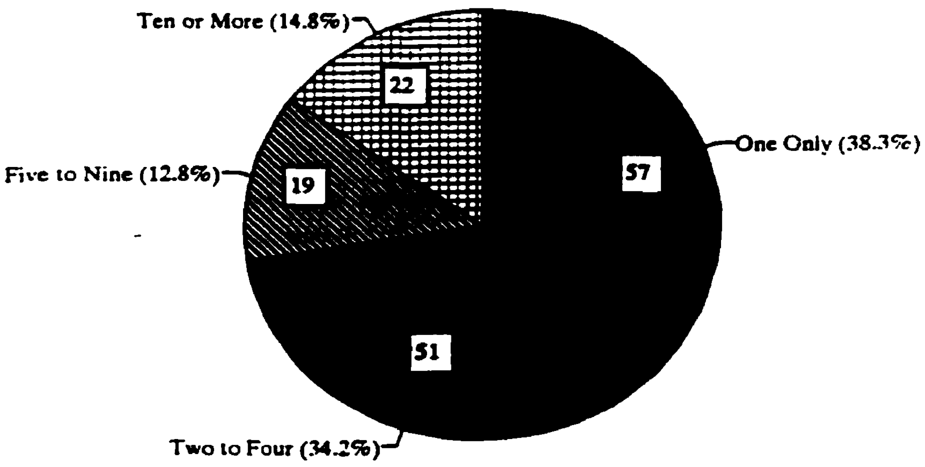
Boxed numbers refer to number of persons

Specifics

Younger children formed a sizable majority of the FAS/FAE persons identified by parents or caregivers. Eighty-seven children (about 34 percent of the total individuals identified) were under 6 years of age and 94 children (about 37 of the total reported) were between 6 and 13 years of age. The survey also captured information for 30 youth and 18 adults ranging in age from 18 to 26 years. Age data was not reported for an additional 25 individuals.

Parents reported that most of the children in their care had been placed in care by a child and family service agency on at least one prior occasion. More than 27 percent reported that their child had experienced at least five (5) prior placements.

Children With Prior Placements in Care Showing Number of Prior Placements
Manitoba Survey of Service Needs Regarding
Fetal Alcohol Syndrome/Effects, 1998



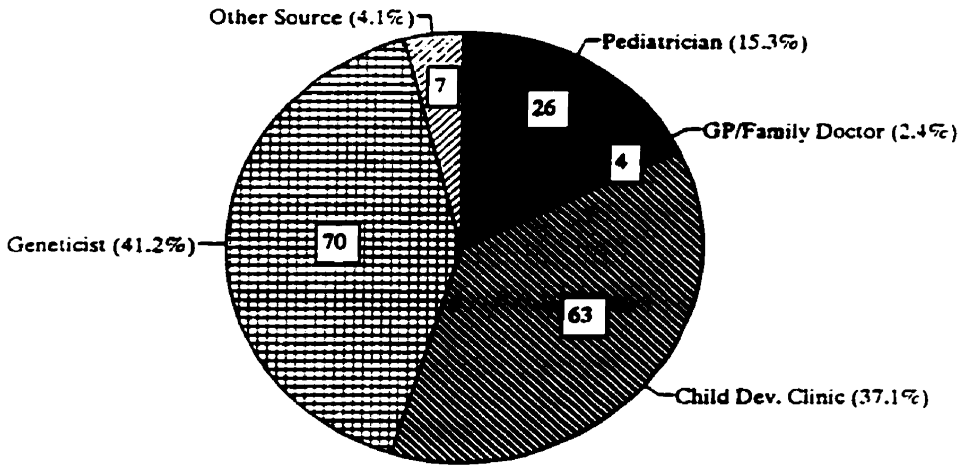
Boxed numbers refer to number of respondents

Specifics

Parents reported that a total of 149 of the children in their care had been placed in care by a child and family agency on at least one prior occasion. This group included 57 (or 38 percent of) children placed on one prior occasion, 51 (or 34 percent of) children with two to four prior placements, 19 (or 13 percent of) children with five to nine prior placements, and 22 (or 15 percent of) children with 10 or more prior placements.

Most FAS/FAE diagnoses were reported to have been made by either the Child Development Clinic or a geneticist. These two sources accounted for about 78 percent of the diagnoses reported by parents or caregivers.

Distribution of Diagnosed Children by Source of Diagnosis.
Manitoba Survey of Service Needs Regarding
Fetal Alcohol Syndrome/Effects, 1998



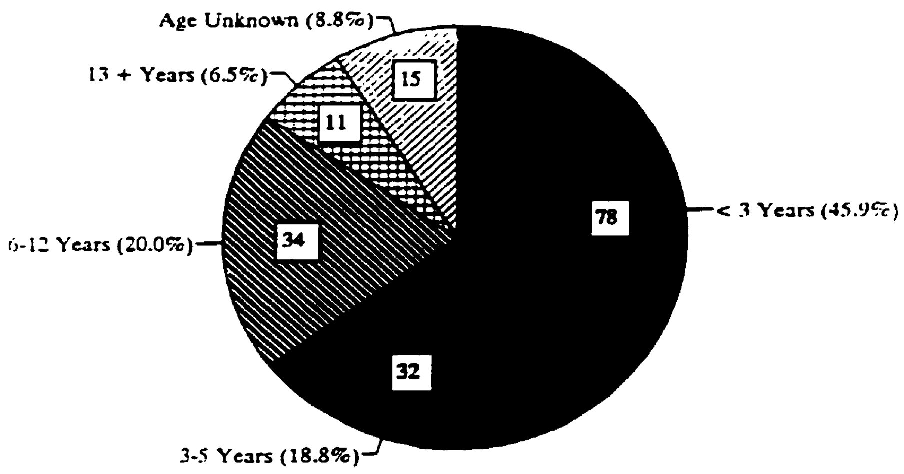
Boxed numbers refer to number of respondents

Specifics

According to parents or caregivers, formal diagnoses were most commonly made by physicians or medical specialists. This group included 143 children (about 78 percent of the total reported with diagnoses) who were diagnosed by the Child Development Clinic and/or a geneticist. An additional 26 children (about 15 percent of those diagnosed) were reported to have received a FAS/FAE diagnosis by a pediatrician. In four (4) instances, diagnoses were attributed to general practitioners or family doctors, while seven (7) cases involved diagnoses made by others. Diagnoses for this latter group were most commonly reported to have been made by psychologists or psychiatrists.

Parents or caregivers reported that most individuals with FAS/FAE were diagnosed at a relatively early age and prior to entering the school system.

Distribution of Diagnosed Children by Age at Time of Diagnosis,
Manitoba Survey of Service Needs Regarding
Fetal Alcohol Syndrome/Effects, 1998



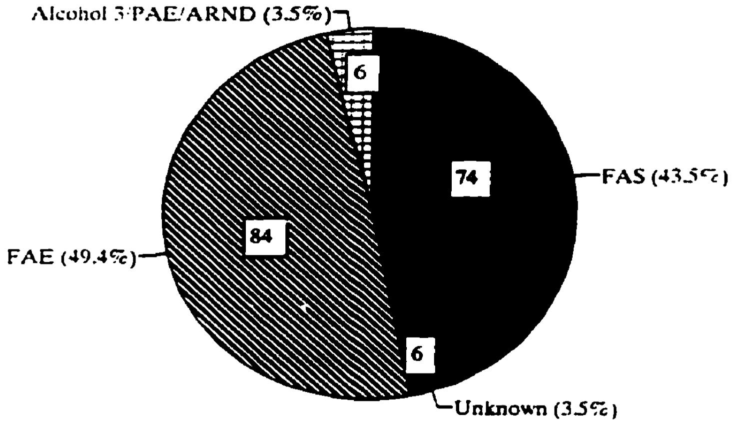
Boxed numbers refer to number of respondents

Specifics

Children under three (3) years of age (at the time of diagnosis) formed about 46 percent of all diagnosed individuals. Children between three and five years of age accounted for about 19 percent of the total. About 20 percent of the individuals were diagnosed between 6 and 12 years of age, while roughly 7 percent were at least 13 years of age. Data concerning age at time of diagnoses were unavailable for 15 individuals (representing about 9 percent of the total reported).

More than three-quarters of the individuals identified by parents or caregivers were reported to have received a formal FAS/FAE diagnosis.

Distribution of Diagnosed Persons in Care by Nature of Diagnosis. Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



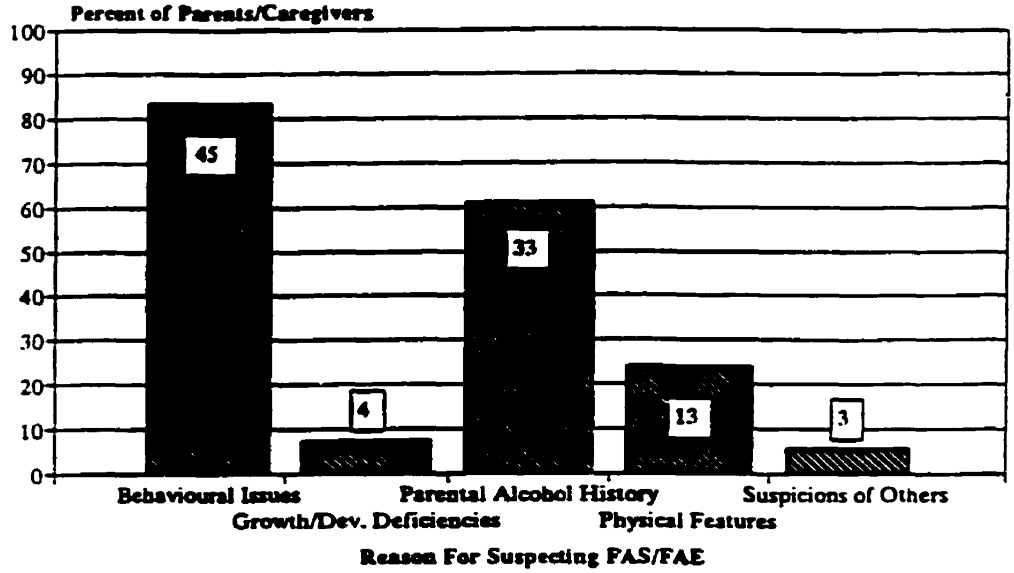
Boxed numbers refer to number of persons

Specifics

Respondents to the parent/caregiver survey reported 170 individuals who had received a FAS/FAE diagnosis. This group included 74 individuals reported with FAS, 84 individuals reported with FAE and 6 individuals reported with other pre-natal, alcohol-related diagnoses (including alcohol 3, PAE or ARND).

In addition to the 170 individuals for whom formal diagnoses were reported, parents or caregivers identified 54 individuals who they suspected of having FAS/FAE. Suspicions were most frequently based on the parent's alcohol history and the child's behaviour.

Proportion of Parents/Caregivers Citing Reason for Suspecting FAS/FAE Among Non-Diagnosed Individuals, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



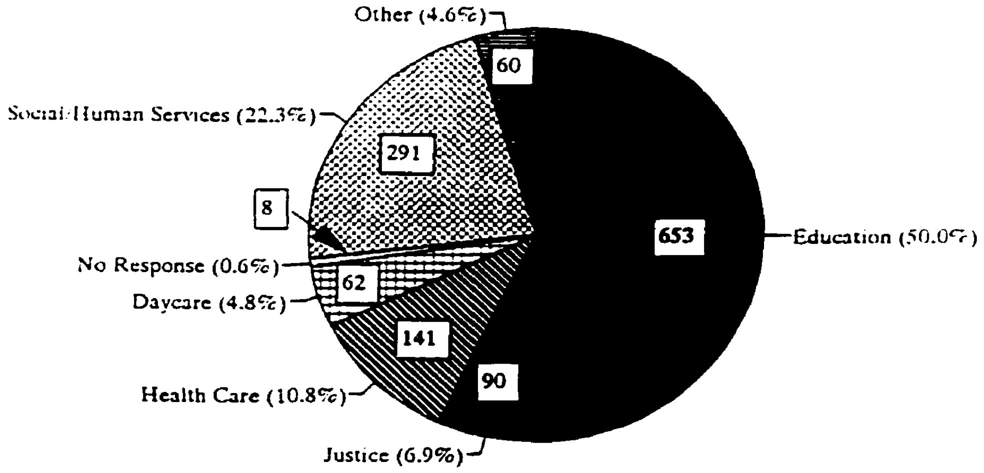
Boxed numbers refer to number of respondents

Specifics

In relation to those individuals for whom a formal FAS/FAE diagnosis had not been made, parents or caregivers were asked to identify the reasons why they believed the individual may have FAS/FAE. Behavioural issues (83 percent of respondents) and parental alcohol history (61 percent of respondents) were cited most frequently. Physical features were noted by 24 percent of parents/caregivers. Other reasons cited included growth or development deficiencies (7 percent) and the suspicions of the other parties (6 percent).

A total of 1,305 service providers also responded to the surveys. Most service providers reported employment in the education, social/human services or health care sectors.

Distribution of Service Provider Respondents by Service Sector, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



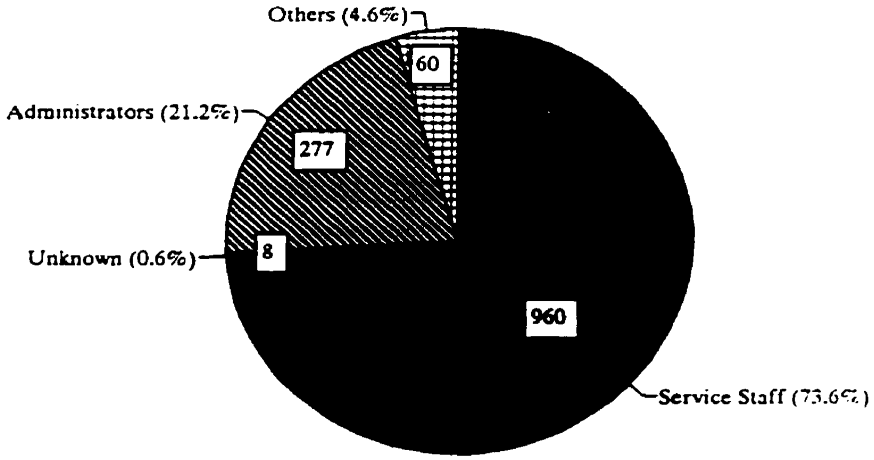
Boxed numbers refer to number of respondents

Specifics

Individuals employed in the education system (50 percent of all service provider respondents) and social/human services (22 percent) formed the largest components of service provider respondents. Individuals employed in the health care sector, justice system and daycare system represented about 11, 7 and 5 percent of respondents, respectively. Sixty (60) individuals (or about 5 percent of the total) reported employment in other fields. This group consisted primarily of employees of various provincial or federal departments, as well as several individuals providing clinical services (e.g. psychologists, counsellors) through a private practice.

Direct service personnel accounted for nearly three-quarters of the respondents to the service provider surveys.

Distribution of Service Provider Respondents by Nature of Occupation.
Manitoba Survey of Service Needs Regarding
Fetal Alcohol Syndrome/Effects. 1998



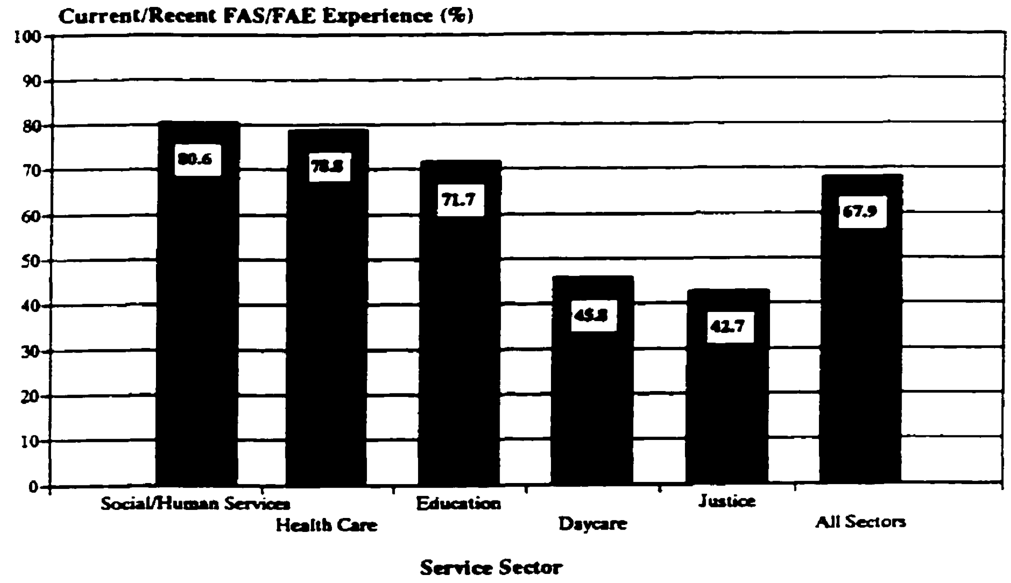
Boxed numbers refer to number of respondents

Specifics

About 74 percent of service provider respondents reported occupations involved in direct service delivery. The largest components of this group included teachers, social/human service workers, special education or resource teachers and health care personnel. In addition to service staff, 277 responses were received from administrators or supervisory personnel. Teachers and daycare administrators formed the largest segments of this group.

Most service providers (about 68 percent) reported current or recent experience and involvement with FAS/FAE persons and/or families.

Proportion of Respondents Reporting Current or Recent Experience With FAS/FAE Persons or Families, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



Specifics

With the exception of workers in the justice and daycare systems, a majority of service providers reported that were either currently providing services to FAS/FAE persons (or families) or had recently (in the last two years) provided services. Current or recent experience with FAS/FAE persons or families was greatest among workers in the social/human services (81 percent of respondents) and health care sectors (79 percent of respondents). Approximately 66 percent of workers in the education sector reported current or recent experience with FAS/FAE individuals. By way of comparison, daycare and justice system workers reported much lower levels of recent experience with FAS/FAE individuals.

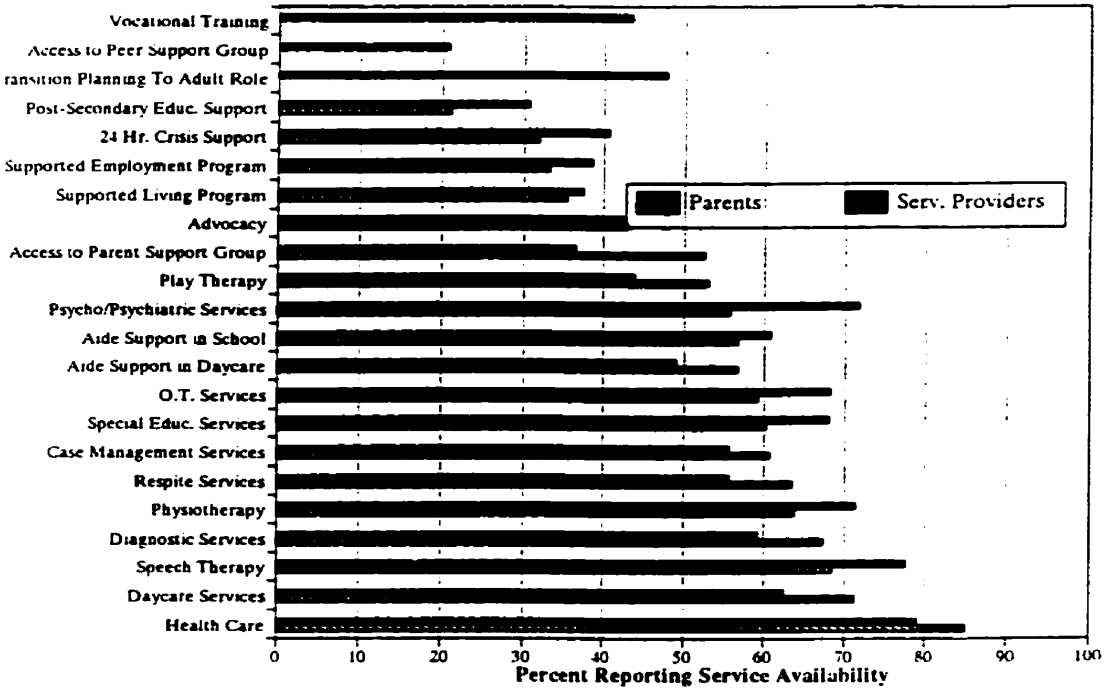
Parents, as well as service providers were provided with lists of services and asked to identify:

- **services available to them,**
- **services which they used (or to which they referred),**
- **services that were not available to them, and**
- **services that were needed (regardless of availability or use).**

Analyses have been undertaken to explore patterns of service availability, **service use, and service need. Needed services were defined to include those either not available or reported to be needed (regardless of availability or use). This notion of need was adopted as many respondents noted that although services were available or used, they experienced difficulties (e.g. waiting lists) in service access.**

In relation to other services, both parents and service providers reported higher levels of availability for health care, speech therapy and physiotherapy services. Services deemed to be least available included parent support group access, advocacy, supported employment and living programs, 24 hour crisis support services and post-secondary education support.

Proportion of Respondents Reporting Service Availability, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

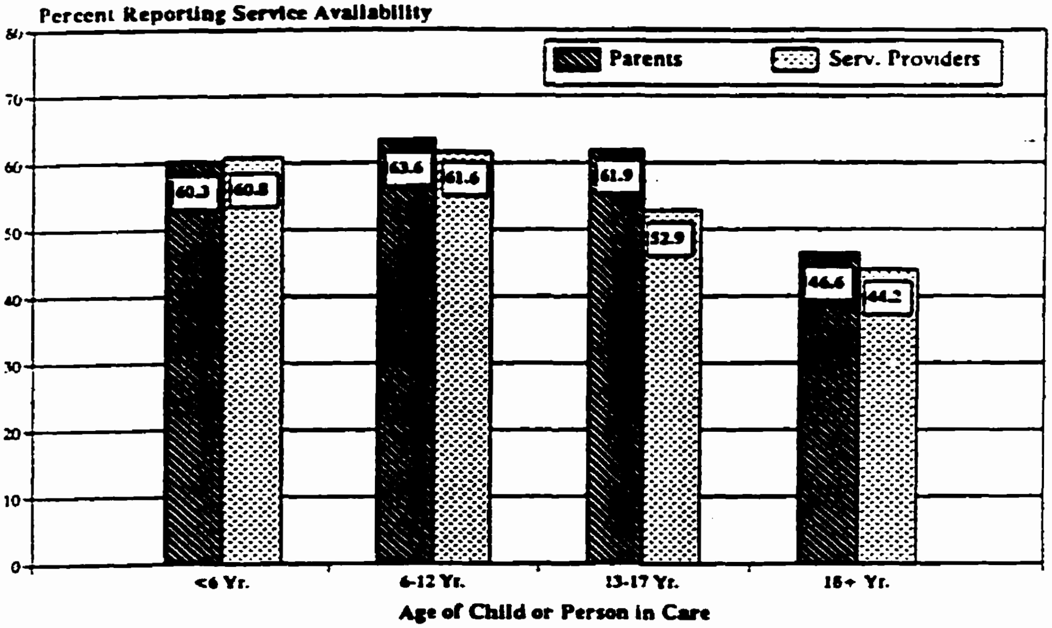


Specifics

In general, a high degree of consistency exists between parents and service providers with respect to service availability. Differences between the two groups concerning which services were most available were limited to a few service categories. Relative to service providers, parents rated the availability of parent support groups, daycare, play therapy and diagnostic services much higher, but the availability of psychological/psychiatric services much lower. Services generally associated with older children and adults (including supported employment and living programs, post-secondary education support, peer support groups, and vocational training) were regarded to least available.

As expected, parents and service providers reported differences in extent of services available to FAS/FAE persons in different age groups. Both groups reported higher levels of service availability for children under 13 years of age and much lower levels of service availability for adults.

Proportion of Respondents Reporting Service Availability by Age of Person in Care, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



Specifics

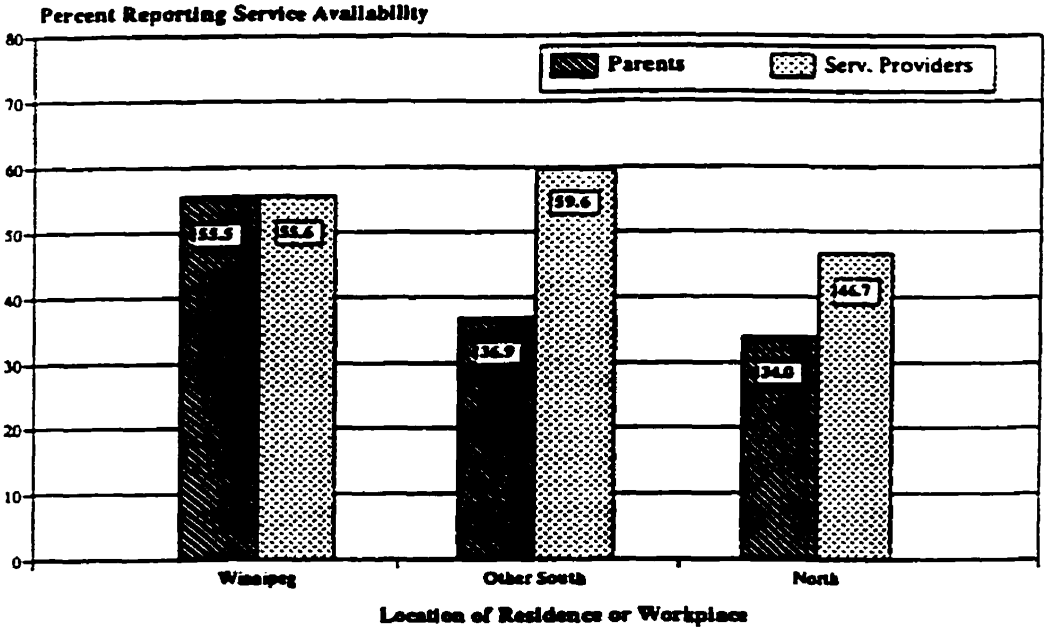
In relation to services for younger children (i.e. under 13 years of age), parents reported the highest levels of availability for health care, daycare, respite, physiotherapy, speech therapy, and psychological/psychiatric services. Least available services for this age group included 24 hour crisis support, aide support in school or daycare, special education services, and parent support groups. For older children and adults, parents reported health care, special education services, aide support in school and speech therapy to be most commonly available. Least available services for this group included post-secondary education support, supported employment and living programs and 24 hour crisis support services.

Service providers reported less variability in the types of services available to various age groups. For most groups, health care, speech therapy, psychological/psychiatric services, physiotherapy, and special education services were reported to be most commonly available. Least commonly available services included peer support groups, post-secondary education, support employment and living programs and parent support groups.

Relative to other age groups, both parents and service providers reported lower overall levels of service available for adults with FAS/FAE.

In relation to Winnipeg residents, northern residents reported lower levels of service availability. Lower levels of service availability were also reported by parents living in non-Winnipeg southern locations.

Proportion of Respondents Reporting Service Availability by Location of, Residence or Workplace, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



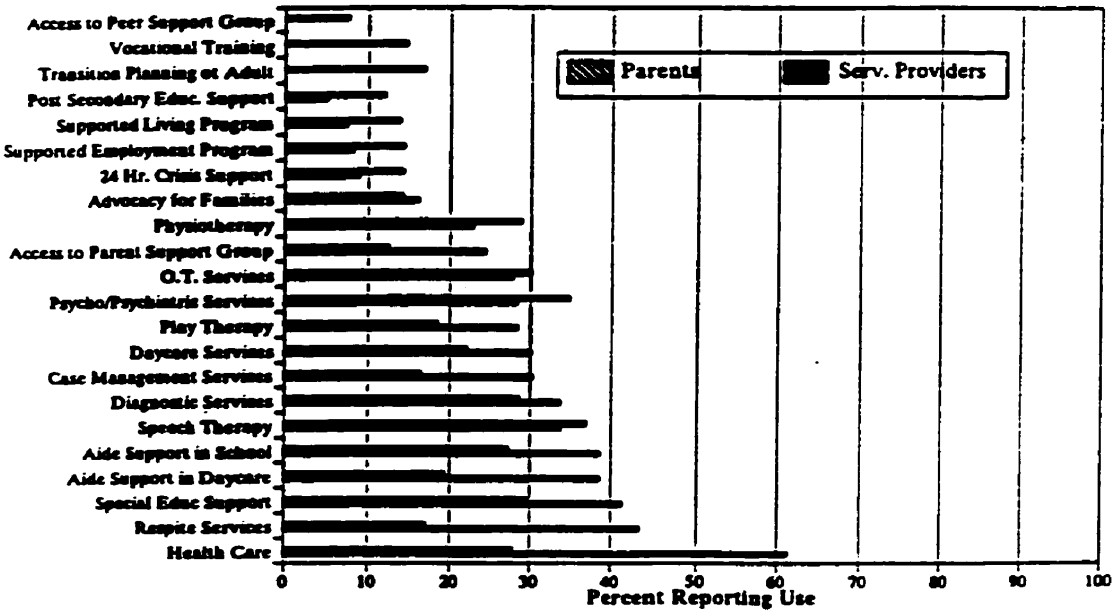
Specifics

Parents in Winnipeg reported higher levels of service availability for all services except supported employment and living programs. Winnipeg/non-Winnipeg differences in availability were pronounced for seven services, including diagnostic services, speech therapy, occupational therapy, play therapy, psychological/ psychiatric services, family advocacy and parent support groups.

Service providers did not identify large differences in the availability of services between Winnipeg and other southern locations, but did report lower levels of availability in the north. Pronounced north/south differences in service availability were noted for occupational therapy, physiotherapy, daycare, diagnostic services, advocacy, 24 hour crisis support, and parent support groups.

Parents reported use of health care, respite, special education, aide support in school or daycare and speech therapy services most commonly. Service providers identified speech therapy, psychological/psychiatric services, physiotherapy, special education support and occupational therapy as those used most frequently. Both groups reported low levels of use for most services generally associated with older children and adults.

Proportion of Respondents Reporting Service Use, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

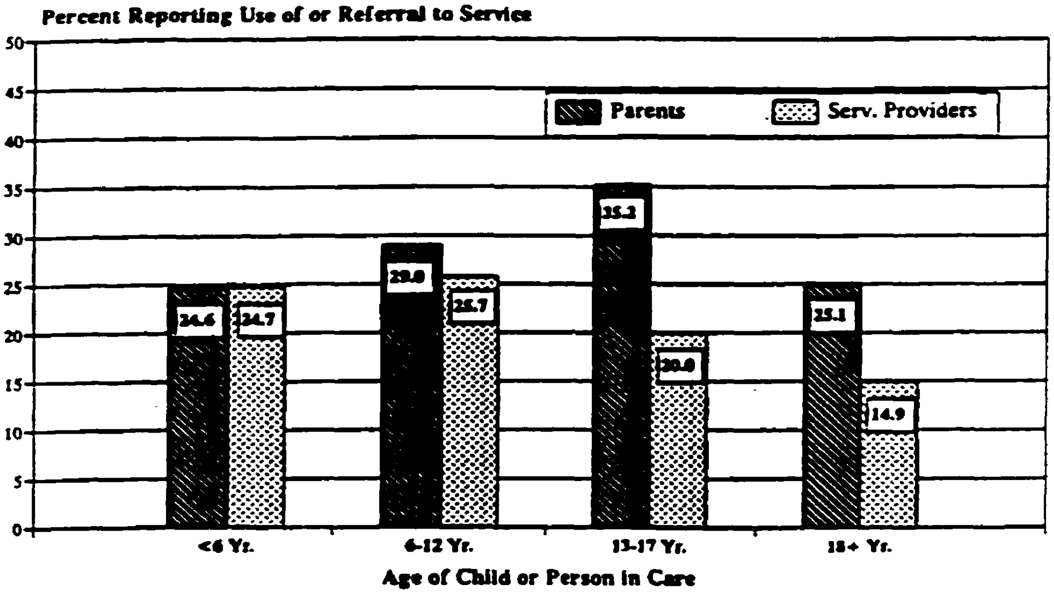


Specifics

Patterns of service use differed considerably between parents and service providers. In relation to service providers, parents were much more likely to report use of health care, respite services, aide support in school or daycare, case management services, parent support groups, daycare and play therapy services. Service providers were more likely to report use of (or referral to) physiotherapy, psychological/psychiatric services, and speech therapy. Low levels of use were reported for peer support groups, vocational training, post-secondary education support, supported employment and living programs, 24 hour crisis support and transition planning to adult role services.

Both parents and service providers reported sizable differences in the use of services for differing age groups. In general, parents reported more frequent use of services among children aged 6-12 years and among youth (i.e. 13-17 years). Among service providers, levels of service use were lowest among youth and adults.

Proportion of Respondents Reporting Service Use by Age of Person in Care, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

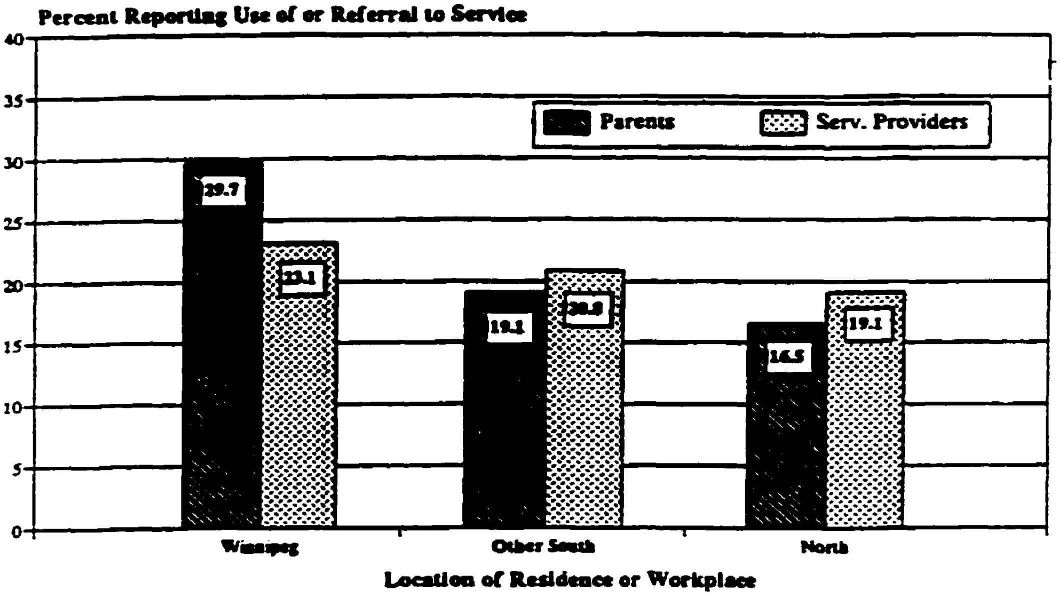


Specifics

Services used most commonly by parents of FAS/FAE children under 6 years of age included health care, respite services, occupational therapy, daycare and physiotherapy. For children aged 6-12 years, health care, special education support, respite, speech therapy and aide support in school or daycare were reported as the services used most frequently. Among older youth and adults, parents reported most frequent use of health care, aide support in school, respite services, and special education support. Service providers did not report large differences in the type of services used by age group. Among service providers, most commonly used services included speech therapy, psychological/psychiatric services, special education services and occupational therapy.

Both parents and service providers reported sharply lower levels of service use outside of Winnipeg. Non-Winnipeg parents were much less likely to report use of speech therapy, physiotherapy, occupational therapy, play therapy, psychological/psychiatric services, family advocacy and parent support groups than their Winnipeg counterparts.

Proportion of Respondents Reporting Service Use by Location of Residence or Workplace, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

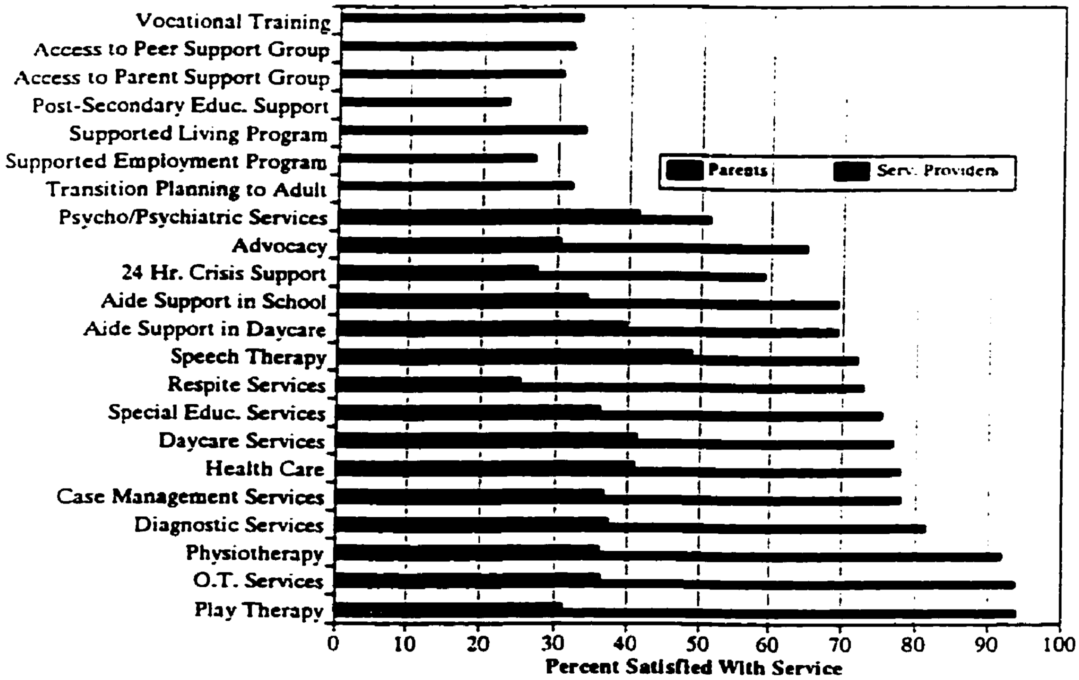


Specifics

In relation to their Winnipeg counterparts, both parents and service providers in other southern locations and in the north reported much lower levels of service use. Winnipeg service providers reported much higher levels of use of several services including physiotherapy, occupational therapy, play therapy, daycare, aide support in daycare, respite, 24 hour crisis support, advocacy, case management, and parent support group services.

In general, most parents that were using services reported high levels of satisfaction with those services. Parents most commonly reported satisfaction with play therapy, occupation therapy, physiotherapy and diagnostic services. Parents were most commonly dissatisfied with family advocacy, psychological/psychiatric services, aide support in school and speech therapy.

Proportion of Respondents Satisfied With Service, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

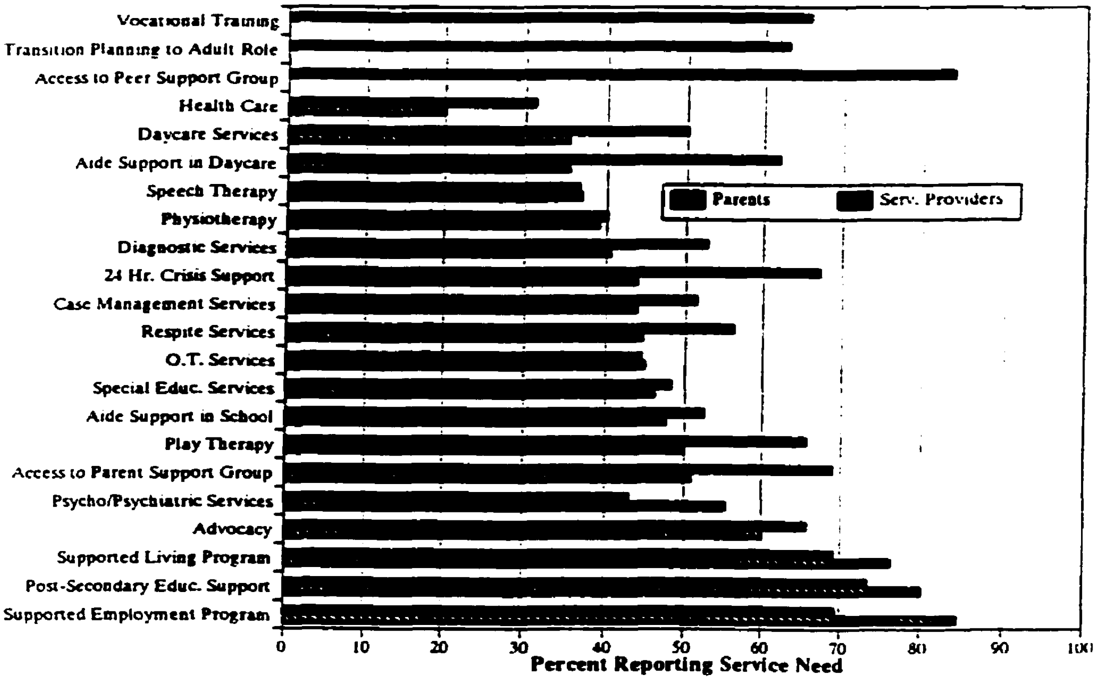


Specifics

For all services for which a sufficient number of responses were received, a majority of parents reported that they were either satisfied or very satisfied with the service. Service providers reported the highest levels of satisfaction with speech therapy, psychological/psychiatric services, daycare, aide support in daycare and health services. Dissatisfaction was expressed most commonly by this group in relation to aide support in school, special education support, post-secondary education support, transitional planning to adult role services, and peer support groups. For parents and service providers, service satisfaction levels did not vary widely among age groups, or among geographic regions of the province.

A majority of parents reported a need for seven specific services. including supported employment and living programs, post-secondary education support, advocacy, psychological/psychiatric services. parent support groups, and play therapy. Similar views were expressed by service providers.

Proportion of Respondents Reporting Service Need. Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects. 1998

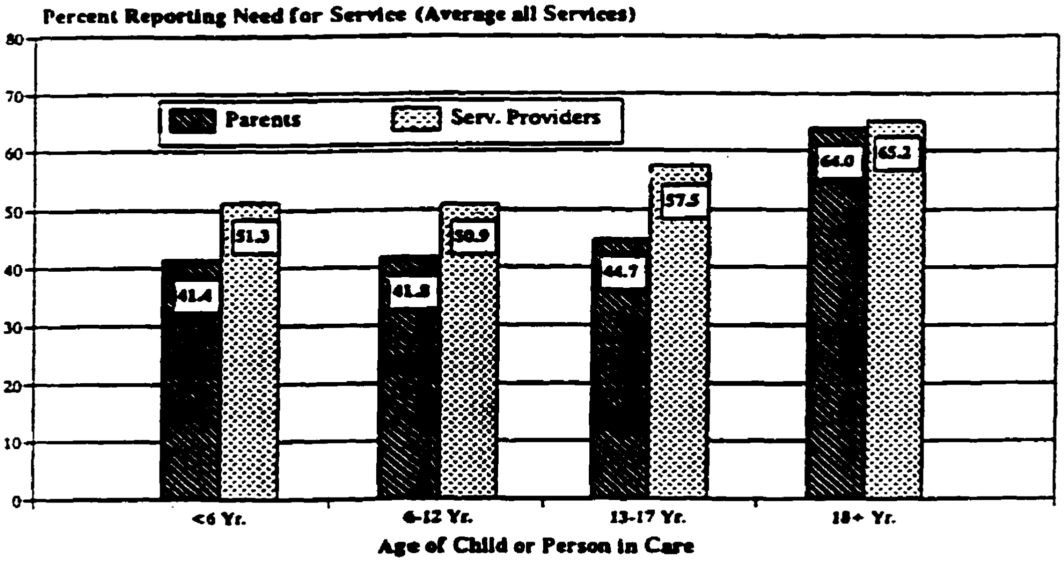


Specifics

Parents and service providers tended to identify the same services as those most needed. A majority of service providers also included peer support groups, 24 hour crisis support, aide support in school and daycare, respite, diagnostic and case management services as priority needs. With respect to case management, parents were most commonly interested in sharing responsibilities for decision making jointly with service providers.

Both parents and service providers were more likely to report service needs among youth and adults with FAS/FAE than among younger children.

Proportion of Respondents Reporting Need For Services by Age of Person in Care, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

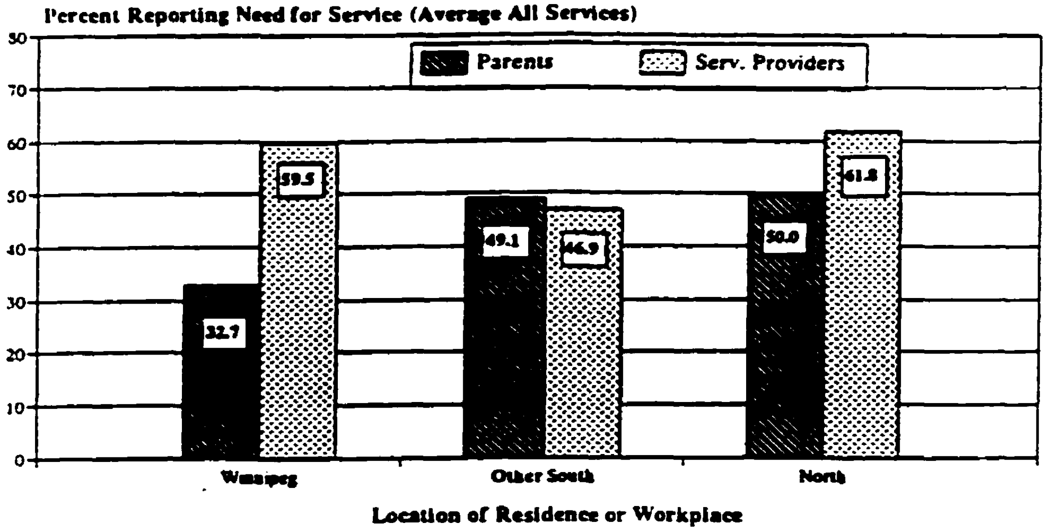


Specifics

In general, a much larger proportion of parents reported service needs for youth and adults than for younger children. Specific services deemed to be needed also varied among age groups. For children under 6 years of age, parents identified speech therapy, diagnostic services, special education support and respite services as those most needed. In addition to the above services, parents of children between 6 and 12 years of age also frequently identified aide support in school/daycare as most needed. Among youth and adults, most needed services included post-secondary education support, supported employment programs and clinical services. Although service providers were in general agreement with parents concerning service needs for youth and adults, this group also identified service needs for younger children to include 24 hour crisis support, parent support groups, play therapy, aide support in daycare, and advocacy as most needed.

Parents living outside of Winnipeg reported much higher levels of service need. Service providers identified needs most frequently in Winnipeg and in the north.

Proportion of Respondents Reporting Need For Service by Location of Residence or Workplace, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



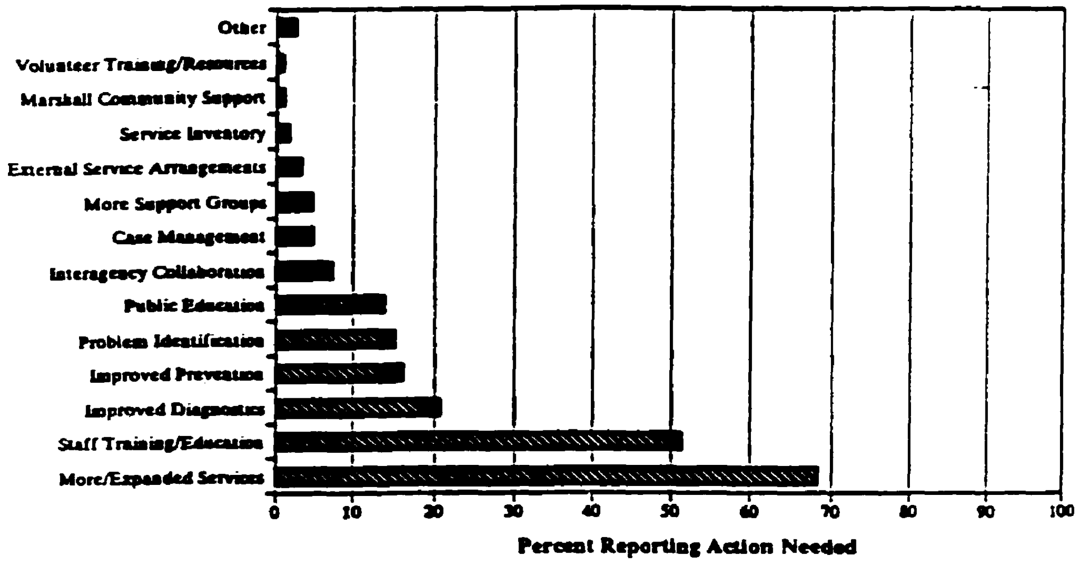
Specifics

Parents residing in different regions of the province identified differing service needs. In Winnipeg, most frequently cited needs included special education services, supported employment programs, respite and speech therapy. Parents in other southern locations reported needs for diagnostic services, respite, and post-secondary education support. Among northern parents priorities included speech therapy, special education, aide support in school or daycare, and respite.

Winnipeg service providers tended to identify service needs associated with youth and adults most frequently. These services included post-secondary education support, peer support groups, supported employment and living programs, vocational training and transition planning to adult role services. In addition to these services, service providers in other southern locations included parent support groups, and advocacy services as priority needs. Northern service providers also included play therapy as a high priority need.

Most service providers identified actions needed in their workplace to improve services to FAS/FAE persons and/or families. More or expanded FAS/FAE specific services and additional staff training and education were identified most commonly in this regard.

**Proportion of Service Providers Reporting Needed Workplace Actions,
Manitoba Survey of Service Needs Regarding
Fetal Alcohol Syndrome/Effects, 1998**

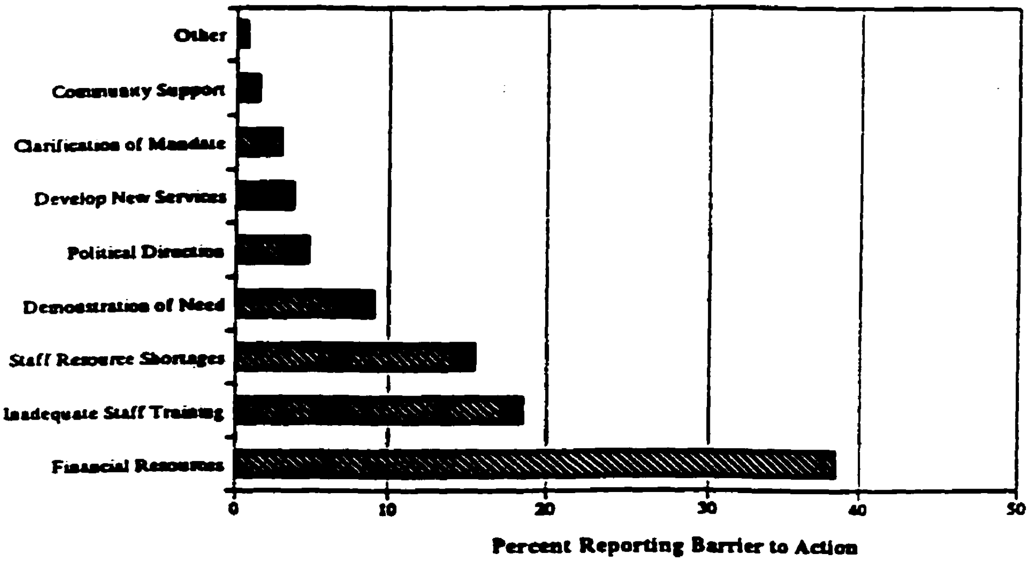


Specifics

A majority of service providers identified two workplace actions needed to improve FAS/FAE services. These included more or expanded FAS/FAE services (68 percent of respondents) and additional staff training or education (52 percent of respondents). Other frequently cited actions included improved diagnostic services/procedures (21 percent), better prevention services (16 percent), identification of the problem (15 percent) and more public education (14 percent). Actions related to staff training and education were identified most commonly by workers in the justice and education systems.

Only 33 percent of service providers that identified needed workplace actions reported that their workplace had plans in place to carry out these actions. Lack of financial resources, inadequate staff training, staff shortages and lack of a demonstrable need for special services were identified most commonly as barriers to change.

Proportion of Service Providers Reporting Barrier to Workplace Actions, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

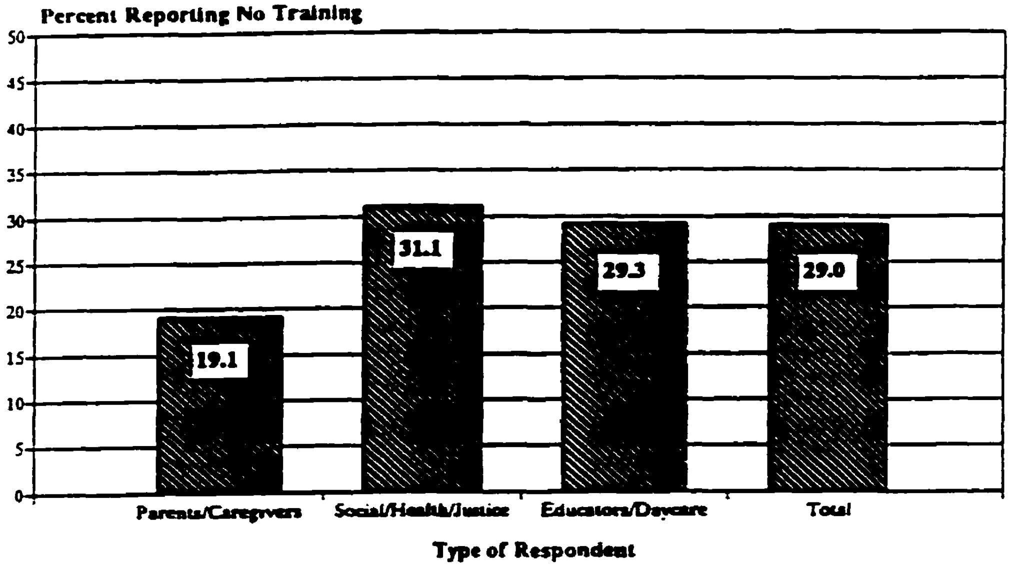


Specifics

Service providers from all service sectors identified financial constraints and staff training or education as barriers to change. Overall, about 38 percent of respondents identified financial resources as a barrier. Inadequate staff training was noted by 19 percent of respondents, while staff shortages and lack of demonstrable needs for special services were noted by 16 and 9 percent of respondents, respectively.

A significant proportion of survey respondents reported no formal training in relation to FAS/FAE. Lack of formal training was more common among service providers.

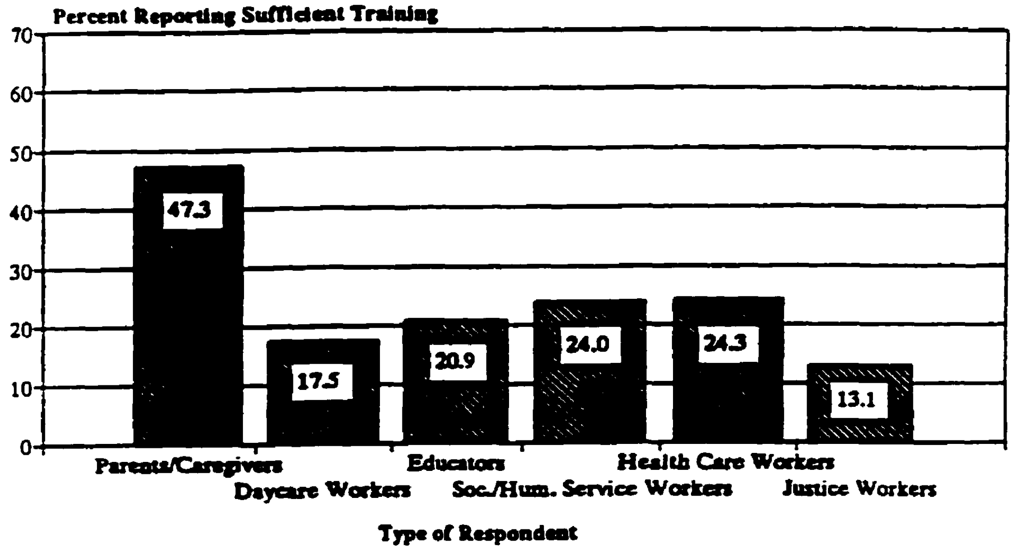
Proportion of Respondents Reporting No Formal FAS/FAE Training,
Manitoba Survey of Service Needs Regarding
Fetal Alcohol Syndrome/Effects, 1998



Specifics

Overall, about 29 percent of survey respondents reported that they had not received any formal training in relation to FAS/FAE. Lack of formal training was reported by 31 percent of workers in the social/human service/health care and justice systems and by 29 percent of workers in the education/daycare systems. By way of comparison , 19 percent of parents or caregivers reported that they had not received formal FAS/FAE training.

A minority of parents and service providers felt that they had sufficient knowledge or information concerning FAS/FAE.



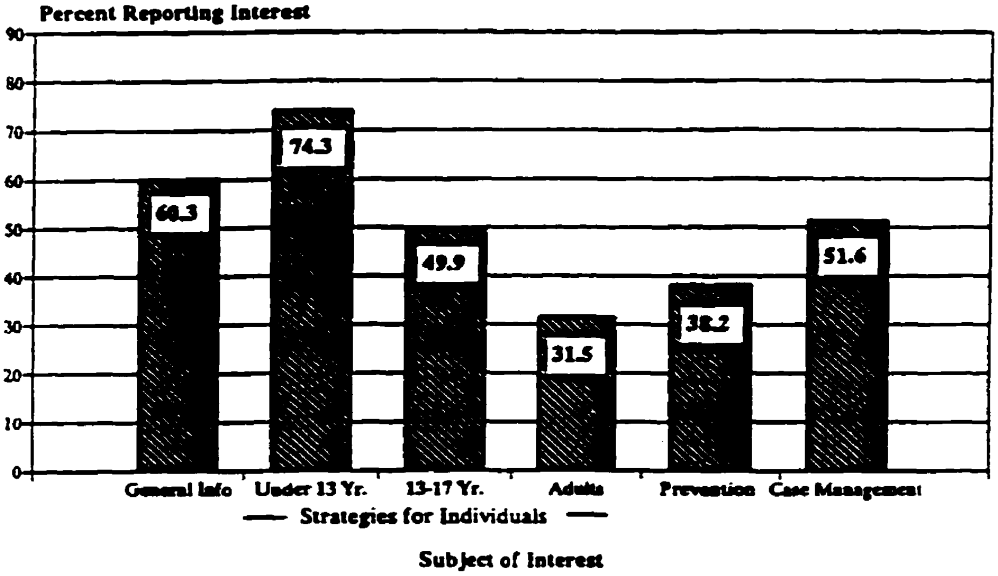
Proportion of Respondents Reporting Sufficient FAS/FAE Training, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998

Specifics

Perceptions concerning the adequacy of current training and information in relation to FAS/FAE varied among sub-groups of survey respondents. Compared to service providers, parents or caregivers were more likely to report that had sufficient information and training. About 47 percent of parents/caregivers reported having sufficient training about FAS/FAE compared to about 21 percent of service providers. Among service providers, satisfaction with current FAS/FAE training was highest among individuals employed in the social/human service and health care sectors (about 24 percent of respondents) and lowest among individuals employed in the daycare (18 percent) and justice systems (13 percent).

A majority of respondents expressed interest in obtaining additional training or information concerning FAS/FAE issues. Strategies for living or working with children under 13 years of age and general FAS/FAE information were identified most frequently as training/information priorities among respondents.

Proportion of Respondents Reporting Interest in FAS/FAE Training, Manitoba Survey of Service Needs Regarding Fetal Alcohol Syndrome/Effects, 1998



Specifics

Roughly 74 percent of respondents identified an interest in obtaining more training or information concerning strategies for living or working with children under 13 years of age. Other high training or information priorities included general FAS/FAE information (60 percent of respondents), case management strategies (52 percent and strategies for living or working with FAS/FAE youth (50 percent). In relation to these issues, lower levels of interest were identified in relation to prevention education (38 percent) and strategies for living or working with FAS/FAE adults (32 percent). Parent were most interested in strategies for living with children under 13 years of age and case management.

Appendix 5 Letter to Ken Murdoch, Winnipeg Child and Family Services

Holly Gammon
7 Bannerman Ave.
Winnipeg, Mb.
R2W 0S9

Mr. Ken Murdoch
114 Wesley
Winnipeg, Mb.

November 9, 1998

Dear Mr. Murdoch:

As per our telephone conversation of November 6, 1998, I am writing to seek access to any data that Winnipeg Child and Family Services has on adolescents and young adults with FAS/FAE.

I am doing a study of FAS/FAE adolescent and young adults for a MSW thesis with the University of Manitoba. I met with Kathy Jones in the fall of 1997, because I knew of her expertise in the topic of FAS/FAE. She told me at that time that she was in the process of developing a survey which would look at the needs of individuals with FAS/FAE. We discussed the possibility of adding a back page to the survey in the hope that I would be able to access it for the purpose of my thesis research. The last page asked people if they would be willing to participate in an interview. It is my understanding that it was added for this purpose. I have requested access to the last page but have been having difficulty obtaining it. While awaiting some resolution on that request, I thought I would seek access to the data base that WCFS has on our permanent wards who have been diagnosed or who are thought to have FAS/E. If this data is made available to me I would then wish to be able to contact the care-providers of some of these children in order to interview them about their experiences.

I am a Master of Social Work student at the University of Manitoba. My faculty advisor is Dr. Lyn Ferguson. (Faculty of Social Work) She can be reached at 474-8273. Also sitting on my thesis committee are Ms. Kathy Jones and Dr. Susan Prentice. In anticipation of completing my degree I am working on my thesis which is a qualitative study of the caregivers who are parenting adolescents and young adults with FAS/FAE. My proposed thesis includes interviewing 15-20 caregivers in order to hear their direct experiences of caring for this particular population. It is my hope to study both the needs of these children in their adolescence and early adult years and the needs of the families who are caring for them. I will then attempt to develop a creative concrete plan for supporting, training and equipping both families and communities for the ongoing task of supporting those affected by FAS/FAE. I am presently at the stage of preparing my thesis proposal. The University requires me to go before the Ethics Committee for approval of my study and research methods later this fall.

I thank you in advance for considering my requests and await your reply. I can be reached by fax at 944-4086 or by phone at 944-4054.

Sincerely,

Holly Gammon

Appendix 6 Consent Form

Researcher:	Holly Gammon 589 - 8993
Advisor:	Lyn Ferguson Faculty, School of Social Work University of Manitoba, Wpg. Phone # 474 - 8273

I have been invited to participate in a study which will look at the needs of the caregivers who are looking after adolescents and young adults effected by prenatal exposure to alcohol. I understand that I have been asked to share my experiences as they relate to my role as a care provider. It is hoped that this research will assist caregivers in accessing the necessary services to enhance the quality of living for this population.

I understand that Holly Gammon will be interviewing me once for about an hour and a half and recording our conversations through the use of a tape recorder. I understand that I have the freedom to not answer any of these questions.

I understand that I may terminate the interview or withdraw from this research project at any time without penalty.

I agree to participate in this study knowing that the taped conversations will be kept strictly confidential and destroyed after the research project has been completed. I understand that the information from the interview will be used for research purposes only, including a research report and publication. I further understand that all identifiable information will be excluded from all disks and written material.

I understand that I may receive a written summary of the results if I request it and that a final written thesis will be available to read at the University Library upon completion.

If I require any further information I can contact Holly Gammon. If I have questions concerning the ethical aspects of this study I can communicate with Lyn Ferguson who is the faculty advisor of this research study. (474 - 8273)

I have received two copies of the consent form, one of which I will keep.

______________________ ______________________

Signature Date

My mailing address is:

____

____

____

My phone number is:

____

The best time to reach me is:

____

Appendix 7 Demographic Information

1. Foster Parent ______ Adoptive Parent _______ Both ______

2. Age: _______ years.

3. Family composition::

Who lives with you? (description and ages)

Other adults: ________________________
Children: ________________________
Are there other family members living outside your home who parent this child(ren)?
(description and ages) _____________

4. Household income: Under $19,9999 _____ $20,000 - 39,9999 _____

$40,000 - 59,999 _____ Over $60,000

Does the majority of your household income come from fostering? _____
Approximately what percentage? ______

5. Ethnic Origin: _______________

6. Years of Experience as a Foster Parent _____. As an Adoptive Parent _____.

7. Children within the household. Number _____.
Male _____ Female _____

Number of biological children presently in the home _____. Ages ________
Male _____ Female _____

Moved out _____. Ages ________.
Male _____ Female ______

Number of foster/adoptive children presently in the home ______. Ages ____
Male _____ Female ______

Moved on ______. Ages _______
Male ______ Female _____

8. Number of FAS/FAE adults currently living at home: _____ Ages ______
Male _____ Female ______

Number of FAS/FAE adolescents currently living at home:_____ Ages _____
Male ______ Female _____

Number of FAS/FAE adults/adolescents you are assisting in a supportive living situation _______ Ages ________
Male ____________ Female ________

9. Training and Education:

Less than grade 12: ____________

Grade 12: ____________

Post Secondary Education ________ Area of Study __________

Training specializing in the needs of FAS/FAE children:__________________

Years: _________ Specific courses: ______________________________
____
____

10. Employment History:
Years working in the home ____________________________

Years working outside the home ________________________

Years in present work situation _________________________

Appendix 8 Interview Guide

1. Tell me about your experience with fostering? (adoption?)

   When did you first begin fostering?

   When did you first adopt?

2. Tell me about the training/preparation you had for fostering? adopting?

3. Tell me what you know about fetal alcohol syndrome/fetal alcohol effects? Did you know this prior to fostering/adopting?

4. Tell me how you first came to wonder whether your child (ren) had FAS/FAE.

   Was your child(ren) eventually given a diagnosis? What was that like for you, for the child (ren)?

5. If you knew you were accepting to foster or adopt a child with FAS/FAE what lead you to make that decision?

6. Is the care for this/these children different than how you would care for a child without this disability? Describe in terms of personal time, family time, the tasks and responsibilities?

7. Who helps you with caring for this child (ren)? (Is this formal/informal: within family/outside family: Paid/unpaid?)

8. What are the burdens, the joys, the special times that make the care for this/these children so meaningful?

9. What are your dreams for your child (ren)?

10. What are the greatest difficulties that you encounter caring for this/these children?

11. Tell me about your experiences with accessing services for your children?

    Medical?

    Child Welfare System (i.e.) information, support, financial assistance, etc.

    Speech?

    Academic?

    Criminal justice system?

    Employment programs?

    Supported living?

    Other?

12. In each of these areas, do you think things could be done differently to make it easier for the FAS/FAE child? If so how?

    For you as a care giver?

13. In your opinion what needs to happen differently in this city/province to ensure that FAS/FAE children are gaining the best possible service to live their lives to their fullest potential?